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A population survey of rheumatoid arthritis

Epidemiological aspects of the syndrome, its pattern and effect on gainful employment

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Contents

Objects of the present investigation

1 To demonstrate, on the basis of official statistics from several sources, the cumulative process of RA (rheumatoid arthritis) cases in the sick-care organization, with respect to age and duration of care.

2. To point out, on the basis of data from the literature, several areas in which selection to sick care occurs.

3 To collect a number of randomly sampled persons, from certain age-groups, residing in Stockholm city with different grades of RA, to serve as a basis for prevalence figures for RA.

4 To study the efficiency of the questionnaire method to concentrate cases with joint symptoms, especially RA cases.

5 To analyse current criteria for RA, their application, validity components, interrelationship, and significance in forming the syndrome of RA.

6. To structurize the pattern of joint involvement in a population material of RA persons.

7 To study the interrelationships between functional capacity and disease progression.

8. To obtain information on the effect of the syndrome of RA on selected medical and social parameters. Special attention was given to somatic function, subjective and objective evaluation of degree of disability and its relation to employment, income, and sick-leave. For reaching a proper dimension of these effects, RA groups were compared with healthy contrast groups from the same population and of the same age and sex.

Official statistics on RA in Sweden[1]

To illustrate the magnitude of the RA problem in Sweden, a survey will be given of various aspects of recent official statistics with special reference to Stockholm. Generally it can be assumed that these figures are based on clear-cut clinical cases and do not include the obscure grey zone between manifest disease and health met with in epidemiology. The figures will therefore represent minimum numbers.

Statistical material

Figures for pure RA morbidity (722.0 ICD, 1961) can be obtained only in some unpublished tables from special investigations. For some tables used in statistics relating to causes of death and sick care the diagnostic number is A 122, which comprises the ICD nos. 720–725 namely arthrosis, spondylosis, and spondylitis. Different classifications for diseases of the bones and organs of movement (ICD 1961 XIII) are used in tables referring to pensioners (1) and to sick listed persons (2, 3). Both types of tables are issued by the same authority the National Social Insurance Board (Riksförsäkringsverket). In tables referring to those reported sick, under heading XIII arthritis is listed together with some other bone and joint diseases, whereas, in statistics relating to pensioners, RA is listed separately both from arthrosis and from diseases of the intervertebral discs.

For inpatient hospital care the statistical material varies with place and specialty from exact figures for well defined diseases to lack of virtually all relevant information.

Mortality

A review of the changes in the mortality rate in Sweden over the period 1957–1966 has recently been published (4). During the observation period the standardized death rates per 100 000 fell for women from 10.28 to 7.68 and for men from 12.02 to 10.96. In these years the autopsy rate increased twofold and is now 42.0 %. During the observation period the proportion of deaths occurring in hospitals increased from 30.4 % to 37.6 %. These two facts render the recent diagnostic data on causes of death more reliable. For 1966, 172 deaths under A 122 included a total of 22 cases of arthrosis and spondylosis, which means that RA was the predominating cause of death; 39 males and 111 females (5). During the period central death rates for A 122 increased for men from 0.2 to 1.4 but decreased for women from 5.7 to 3.0. Even if figures for arthritis, spondylitis, arthrosis, and spondylosis are presented together under the heading A 122 (Nos. 720–725 ICD 1961) the proportion of RA can thus be estimated.

Swedish mortality figures are in accordance with figures from other countries presented by Sze (1963). Changes are of course difficult to interpret. One explanation may be that, nowadays, rheumatoid arthritis is not accepted as the main cause of death and, so, other underlying causes (e. g. infections) will predominate. Urinary infection, for instance, is recorded as the cause of death in a markedly increasing number of cases (4). RA is relatively seldom reported as the sole cause of death (Olson, 1962). Reah (1963) found that RA was mentioned on the death certificate only for 43 of 80 known cases. It is, of course, possible that the increase might be of purely administrative nature and would not mirror a true change in the disease panorama.

Disability pension

Statistics have recently been published (1) on the total number of disability pensioners in 1966 distributed by diagnoses and age between 16 and 66 years special tables for Stockholm were made available (6) (Fig. 1). The following facts will

[1] Numbered references, in brackets appear on p. 144 in the reference List.

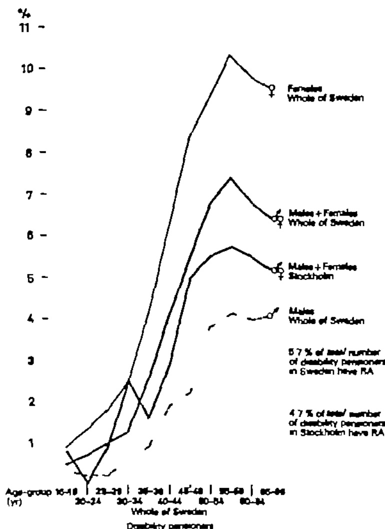


Fig 1 Persons drawing disability pension for RA as percentage of total disability pensioners in different age-groups (1966).

illustrate the conditions in Stockholm. 10.14% (787 183 inhab. 1 Nov 1965) of the population of Sweden reside in Stockholm City (7). The distribution by sex and age for Stockholm City (Population and Housing census in 1965) differs from the average for the country. In 1965 the proportion of women in Stockholm was 51.29% as against an average of 50.04% for the whole country. This excess of women covers mainly the ages above 54 and increases with age. In the ages 55–59 for instance, the ratio women/men is 1 010/1 000 in Sweden, as against 1 190/1 000 in built-up areas with more than 100 000 population. In the ages 70–74 there are 1 200 women to 1 000 men in the whole country and 1 500 women to 1 000 men in these built-up areas.

With this sex and age distribution Stockholm should, accordingly present a greater number of RA cases. But, although these figures indicate a higher RA prevalence, the proportion of pensioners with RA is lower than the national average. Some explanations of this may be 1) the centralization of specialized and successful care in Stockholm, 2) that outside Stockholm area a greater number of cases are diagnosed as RA on less strict criteria, and 3) a greater number of pensioners in rural areas, as pensioning is a sociomedical measure in distressed labour-market situations.

As regards partial pensions (one-third or two-thirds of full pension), the proportions of RA patients are higher): 3.4% for the men and 11.5%

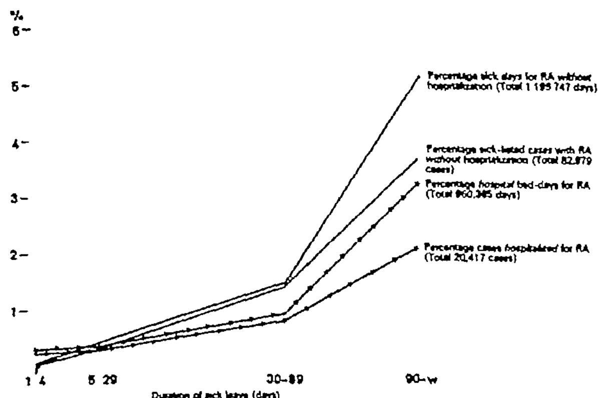


Fig. Sick care for patients with RA (ICD 722.0). Sample from the whole of Sweden 1966.

for the women who draw such pensions (116 out of 3 414 *men* and 702 out of 6 124 *women*) (1).

Sick leave and hospital care

From the recently published statistics on sick leave and hospital care some figures for 1966 can be obtained which are representative of the whole of Sweden (2). By special request, separate figures for RA (722.0) were made available (8). The mean number of sick days for cases with RA in 1966 were for men 117 days and for women 114 days. *Fig.* _ shows the proportion of bed-days and inpatients with RA (72_.0). Figures for Stockholm separately are not available. The greatly increasing proportion of RA cases is noted in all the groups with increasing length of hospital care and sick leave. The proportions of RA patients with or without hospital care among those sick-listed are also shown in Fig. 2. Among the total number of those who had been on sick leave for more than 90 days 37.9 per 1 000 had RA. The proportion of RA persons of those with 90 or more sick days is still greater being 52.5 per 1 000.

Totally the proportion of RA patients with hospital care is higher than that of RA patients without hospital care.

The picture of RA as a long-term non-fatal disease to a great extent requiring long-term hospital care is clear from the official statistics.

Hospital statistics from Stockholm

The estimation of the number of Stockholm citizens hospitalized for RA is complicated for the following two reasons. *Firstly* RA patients are treated within many different sick-care organisations inside as well as outside Stockholm, for instance hospitals providing acute care, hospitals providing chronic care and the hospitals of the National Social Insurance Board. *Secondly* central hospital-care statistics arranged by diagnoses are available only for the acute hospital service which means that central diagnostic data for all hospitalized RA patients are lacking, as are general diagnostics relating to the outpatient service. In the whole of Sweden in 1955 for all inflammatory rheumatic diseases, the mean length

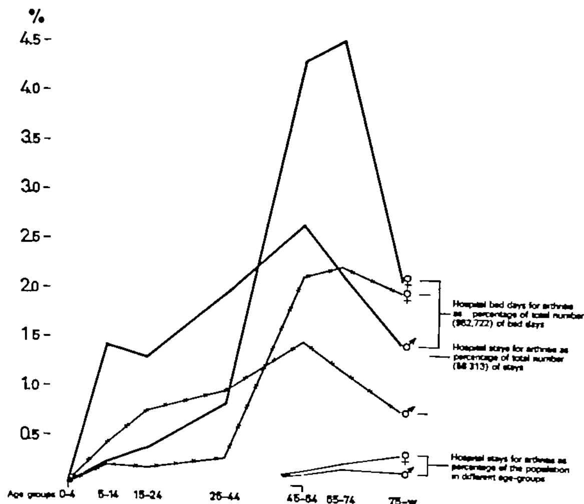


Fig 3 Proportions of arthritis and spondylitis (ICD 720–725) A 122 in hospital statistics of Stockholm (1964).

of hospital stay within *some* sectors of hospital care varied between 28 and 62 days (26). There are some ways to estimate the magnitude of hospital care.

There are, however not yet published data on the diagnostic group A 122 from the four bigger hospital groups in the city (Södersjukhuset—Sachska barnsjukhuset, S:t Görans sjukhus—Garnisonssjukhuset, S:t Eriks sjukhus, and Sabbatsbergs sjukhus) (9). The number of cases and proportions by age-groups and sex are demonstrated in Fig. 3. In age-groups 45 years and over the female RA cases have proportionally more hospital bed days than have male RA cases. The RA proportions of both the number of hospital stays and hospital bed days fall but not continuously in the three age-groups 45–64 65–74 and 75–ω This probably reflects both the transfer of RA cases from acute to long-stay hospitals and the difficulties for elderly people to be admitted to acute hospitals.

The RA cumulation process is, however clear and considerable.

Unfortunately these figures are not correct if they are taken to refer to pure RA cases, because arthrosis is also recorded under the heading A 122. At the time of writing, the latest published information useful in correcting the A 12. figures is that from 1963 (10). Figures refer to inpatients discharged in 1963 Out of 401 persons hospitalized under A 122, 87 (21 %) had arthrosis treated in the orthopaedic clinics. For 1964 it can be assumed that the proportion of RA cases would be unchanged and, therefore, the number of pure"

RA cases treated in hospital in 1964 can be estimated at *472*

For this reason the initial figures are reduced by one-fifth but cases are added from several other forms of inpatient care. To make a comparison possible with the large and latest patient inventory of 1965 (11) the figures will in the following refer to 1965 Information is mainly collected from unpublished sources. The figures refer only to residents of Stockholm city

(*a*) *149* patients were treated in the department of Rheumatology at Karolinska sjukhuset (12).

(*b*) *8* patients were treated in the hospitals for rheumatic diseases at Strängnäs (13) and Spenshult (14).

(*c*) A total of *86* patients were treated in hospitals of the National Insurance Board (69 at Nynäshamn, 16 at Tranås, and 1 at Åre) (15).

For the remaining parts of inpatient care, mainly long-term care, preliminary data are so inconsistent that they will only allow estimates.

(*d*) Sturby nursing home the largest of the nursing homes of the Stockholm City Social Welfare Board, admitted 9 cases of RA (16) to its 860 beds, which comprise 34% of all available beds within this administrative section (17). The total number of RA cases within the section is estimated at 7 The total number of patients with RA taken care of during 1965 was not obtainable but must be higher which should be observed at the estimation of total inpatient care.

(*e*) In Blackeberg hospital, the largest of the long-stay hospitals of the Stockholm City Medical Services Administration, 66 RA cases were hospitalized on a total of 315 available beds (18). One-third of these patients were hospitalized for more than one year The figures should therefore be reduced by one-third, which gives 44 RA cases. In 1965 the total number of beds in this administrative section was 539 The number of RA cases in the section should therefore be increased by 48.4 in round figures 50 e.g. 22 cases giving a total of *66* cases.

(*f*) For about 800 beds in several small private nursing homes statistics on diagnoses are lacking or are highly incomplete. A reasonable estimate of the number of RA cases for 6% of the beds in this section would be *50*

(*g*) *30* patients with RA, being residents of Stockholm City received official care in hospitals abroad (Jugoslavia) (19).

Summarizing a total of 903 patients with RA received hospital care in 1965 Only 52% of them appear in the official statistics published by the Stockholm City Medical Services Administration.

As regards the sections (a) to (g) some changes have up to now (Jan. 1970) been made in two of them.

1 In the long-stay hospitals of Stockholm City Social Welfare Board and Stockholm City Medical Services Administration, now under the same administrative unit, the number of beds has been increased by 785 (2_7%) (20). Assuming that the proportion of RA cases has remained unchanged (6%) this adds only 47 RA cases to this section of long-term care.

2 In 1968 official care abroad (Jugoslavia) comprised 227 cases of RA (21), which implies a 7 6-fold increase. This section is now one of the three main sections of inpatient care of Stockholm citizens with RA.

Point prevalence of RA cases in inpatient care in Stockholm

The last patient inventory in the Stockholm area, made on Nov 17 1965 lists 205 cases of RA out of 13 703 (1.5%) provided with different forms of inpatient care in Stockholm City but it was impossible to separate exactly County patients from City patients (22).

Although showing some data on *consumption* of care this inventory was intended to serve as a basis for standards for *need of care* This definition is inadequate but commonly used e.g. by Berg & Tillman, 1959 and in official reports (23).

Out of these 205 RA patients, 47 received acute care that is, in short-stay units 158 patients received long-term care. A further 4 were on the waiting list for inpatient care and another 5? were nursed at home on public allowances.

As regards patients with RA who had applied for and been found to qualify for inpatient care only 47 out of 299 or 16% received acute care

Estimation of average length of hospital care for long-stay RA patients

In 1963 the average length of hospital care (average number of hospital days for a patient in acute care for A 1__) in Stockholm was 35 days for males and 38 days for females, averaging 37 days (10)

By calculations using the foregoing data, the unknown length of hospital care for the average long-stay RA patient can be estimated.

Conditions necessary for this calculation are:

1 Hospital periods both for long-stay and for acute beds should be uniformly distributed over a long period of time (several years).

2. All patients in long-stay units are given a hypothetical maximum stay time of one year

Applying these conditions and using the figures on RA from the patient inventory of 1965 (22), the following calculations can be made:

$$\frac{\sum_{k}^{N} Li}{\sum Si} = \frac{158}{47}$$

N = Number of RA patients in long-stay units during 1 year = 287 cases,

N = Number of RA patients in acute units during 1 year = 621 cases,

Li = Length of hospital care of individual long-stay RA patients,

Si = Length of hospital care of individual short-stay RA patients = 37 days.

The ratio 158/47 should thus be equal to the sum of hospitalization time for each category:

$$\frac{1}{N} \sum Si = 37$$

$$\sum Si = 621 \quad 37 \text{ days for one year}$$

$$\sum Li = \frac{158 \quad 621 \quad 37}{47}$$

$$\frac{\sum Li}{N} = \frac{158 \quad 621 \quad 37}{287 \quad 47} = 269 \text{ days}$$

The average time (Number of inpatient hospital days/Number of new admissions per year) for long-stay hospital care in Stockholm in 1968 was 111–122 days (24). The average long-stay RA patient was therefore hospitalized at least 2.5 more days than the average long-stay patient. In the US in 1964 the mean duration of stay for a nursing home patient with arthritis or rheumatism was 2.1 years (25).

Conclusions

The proportions of RA cases among those being hospitalized showed a 10-fold increase from the shortest to the longest period of hospital care. Among those not being hospitalized but on the sick-list this increase from the shortest to the longest period of sick leave was 150-fold.

For long sick periods, both outside and inside hospital, proportionally more time than cases are represented by RA. This implies that, within a given duration of time, RA cases have a greater part of the long and a less part of the short hospital stays than those with other diseases.

The inpatient care of RA cases in Stockholm is provided in a large number of institutions, offering great variations in possibilities of obtaining information on this form of care. During one year 68 % of the hospitalized RA patients were taken care of in acute hospital wards, but only 16 % received such care at a point prevalence study in the same year The average length of hospital stay for RA patients in *acute care* is 37 days but for *long-stay care* it is estimated at 269 days, which is more than twice the average reported for some long-stay units.

The use of different diagnostic classes and different definitions of hospitalizations impair detailed statistical information on RA. These difficulties are accentuated by the incompleteness in central hospital statistics and lack of continuous information on diagnoses in outpatient care. However some data on general sick-care consumption of RA patients provide acceptable information.

The ever-increasing cumulation of RA cases in longer sick periods and higher ages outside hospital, in acute hospital stays, in long-term hospital stays, and in the disability pensioners' group is great and occurs in different sections of sick care.

Population studies of the rheumatic diseases

Why population studies of diseases?

There is one main argument for studying diseases and symptoms of diseases by population surveys. The various selections that inevitably occur in any hospital material dealt with in textbooks of epidemiology (e. g. Morris, 1964) are mostly avoided. From this follows that the disease and its symptoms in a population survey will be studied in its full spectrum which is essential to our understanding of disease patterns, effects, and prognosis. These problems have been discussed by Kellgren (1966, 1969) and Laine (1965). A diagnosis should be expressed as a degree of probability rather than as a simple yes-or-no alternative. This is pointed out by Elsom et al. (1967) and exemplified by hypertension, diabetes, and overweight. Some references on the numerous selection mechanisms recognized in a hospital series are reviewed in Table 1 Some of them are of a general nature others refer to RA or joint symptoms.

Development of methods. Main areas of investigation

General remarks

The ultimate goal for population studies has been to reveal the causes of RA but, so far data of dramatic and crucial importance in this respect have not been produced. However the first step towards knowledge on the pathogenesis is an answer to the question, "What is the significance of the elements in the RA syndrome?" Data from population studies on the rheumatic diseases have meant an important contribution to this question.

For RA the step from the hospital world to full-scale population surveys has been taken gradually Different sources of official statistics have been used in some early investigations from the 1920s and onward and have been reviewed by Hargreaves (1957) and in a WHO publication (1954). Large-scale population investigations using broad definitions of rheumatic diseases have been performed in Sweden by Edström (1944 1946). At the end of the 1940s, British investigators, topped by Lawrence & Kellgren, started to study rheumatic diseases and symptoms in Great Britain. Although many have contributed to the development in this field, the efforts, results, and impulses of Kellgren & Lawrence occupy a central position, and their studies are still in active progress.

Several reviews of investigations and results in epidemiology of rheumatic diseases have been published (Lawrence 1963 *a* and *b* Kellgren, 1964, 1966, 1968 *a* Miall, 1968 Wolfe, 1968 Hargreaves, 1957 Scotch, 1962). The report on the survey by Adler et al. (1967 *a*) contains a table of 26 earlier investigations with population sizes, methods, etc. Two monographs (Kellgren et al. 1963 and Bennett & Wood, 1968) on results of international conferences on the subject are the main sources of information.

Therefore only a brief description of the development in this field will be given here, together with some main spheres under discussion.

Initiation of criteria

In the investigation by Kellgren et al. (1953), and its follow-up by Kellgren & Lawrence (1956), basic symptoms and signs were listed together with diagnoses of inflammatory and degenerative joint diseases in 1 407 vs. 537 persons. The central position of radiology in the diagnoses of RA was focused and classifications of inter and intraobserver errors recognized (Kellgren, 1956 Kellgren & Lawrence 1957 *a*). For intraobserver error concerning grading 0–4 for RA the correlation coefficient was 0.91 but for osteoporosis there were wide differences in grading.

Miall (1955) was the first to use more exact criteria for RA in a population study comprising 74 persons suspected of having RA in a population of 9 430 in a Welsh mining community

In a similar study made later by Miall et al (1958), however it was noted that no definite

Table 1 *Some areas of selection bias in patient series*

Items	Author	Year	With special reference to RA	Main comments on selection
General problems	Berkson	1946	No	False associations between diseases appear according to different probabilities of hospital admission
	Elinson & Trussel	1957	No	Under-reporting of symptoms general problem
	Ekblad	1959	No	Studies of selection bias in applied statistics
	Lawrence	1960	Yes	Some rheumatic cripples never attend hospitals
	Laine in discussion den Oudsten	1960	Yes	Surveys necessary for information on social importance of RA
	White et al.	1961	N	9 persons out of 750 sick in population of 1000 are hospitalized each month. Little is known about hat actually brings sick person to doctor
	Stoeckle et al.	1963	No	Population surveys always find great number of diseased persons, who are aware or not aware of their diseases but ho are not under medical care
	Short	1968	Yes	(On patients admitted to special clinic) constitute ill-defined selections from the total number of persons with this disease in the general population"
	Andersen	1969	No	False associations between diseases appear according to different probabilities of admission
	Tanba	1969	No	In the medical literature there is general lack of information on how sampling of contrasts and probands was really performed. Population at risk therefore not possible to define. Careful matching necessary
	Wulff	1969	No	An analysis of diagnostic process shows the arbitrary boundaries of diagnosis for disease of unknown origin
Age	White et al.	1961	No	Generally the same consultation frequency in age-range 15–44 years and over
	Kasl & Cobb	1966	N	Individuals over 60 are either high or low consumers of sick care. Proportion of those never seeing doctor is rising with age
	Olsen	1968	N	70–80 % of old people, irrespective of age, considered themselves in good health. Doctor rated only 19–40 % in good health
	Purola et al.	1968	No	Only 12 % more consultations in age-group 65–74 than 45–54 years. The same consultation frequencies in 55–64 and > 75 years
Sex	Densen et al.	1959	No	Women highly over-represented among those having > 10 doctor' visits. Men over-represented by 20 % among those with no consultations
	Purola et al	1968	No	Women 15–44 years old have 50 % higher number of consultations than have men of the same age
Income	Engel et al.	1966	Yes	Income groups below $ 2000 have twice as much RA as expected
	Kasl & Cobb	1964	No	Higher participation in free polio vaccine programs among those with higher incomes and higher education
	Olsson	1967	No	Higher rates for sick leave in income classes below 1500 Sw. kr./month both for men and women
	Purola et al.	1968	No	T ice as much prescription medicines used in low as in high income groups
	Purola et al.	1968	No	Consultation frequency is doubled from lowest to highest income class
Social class	Koos	1954	No	For given symptom low social class consider themselves needing considerably less medical attention than do high social class

Item	Author	Year	With special reference to RA	Main comment on selection
	Kedward	1962	No	23 % of consultations in social class I were made over the telephone, as against 1 % among others. Twice as many from lower as from higher social classes were sent to hospital
	Kemp	1967	N	In 900 surgical and medical patients, social classes I–II were under-represented, being half as common, and social class V was over-represented, being three times as common as their respective proportions in the population
	Pickles & Ireland	1969	No	"In general, lower social class is associated with a lower utilization of health services but higher measures of poor health"
Area	Jonsson & Widén	1958	No	Twice as many disability pensioners in age-group 50–66 years in northern part of Sweden (Norrbotten county) as in southern part (Kristianstad and Malmöhus counties)
	Purola et al.	1968	No	Falling consultation rates with increasing distance to nearest physician. Doubling rates for hospital care for chronic sick in areas with high vs. low numbers of doctors
	Waife	1968	Yes	Low prevalence of positive answers to questions on arthritis in north-eastern part of the USA, although the population in that area is older than in the rest of the USA. Effect of low incomes?
	Spri-report	1969	No	More hospital consultations and less district nurse consultations in urban than in rural areas
General economic climate	Olsson	1967	No	Absenteeism is high during periods of good general economic climate and low in bad general economic climate
General health and sick care organization	Smedby	1968	No	Number of hospital beds for acute care per 1 000 population in the USA 3.7, in England and Wales 4.4, and in Sweden 6.0. Twice as many outpatient consultations in the USA as in Sweden. Pronounced differences in numbers and use of hospital beds between countries
Demand for medical care	Mechanic	1959	No	"The capacity of hospital or clinic to care for patients may well influence the decision as to whether or not given patient's illness is defined as requiring hospital admission or clinic care and, if so, for how long
	Smedby	1966	No	Demand for medical care generally correlated with supply. Actual consumption of medical care is often falsely accepted as measure of justified demand
Individual attitudes towards health and disease	White et al.	1961	No	Official statistics give no information on what brings a sick person to a doctor
	Mechanic	1962	No	"For some illnesses at least its appearance in medical statistics may be as much result of patterns of illness behaviour and situational events as it is of the symptoms experienced"
	Stoeckle et al.	1963	No	Official statistics give no information on what brings sick person to doctor
	Stoeckle et al.	1963	No	"The characteristic fact that differentiates patients from non-patients is not the seriousness of his complaint nor its treatability"
	Stoeckle et al.	1964	No	Up to 88 % of new patients of medical clinic stated some psychological disturbance, more common in females than in males

Item	Author	Year	With special reference to RA	Main comment on selection
	Mechanic & Newton	1965	No	Illness behaviour, e.g. the way symptoms are comprehended and evaluated by sick person, has considerable influence on consumption of sick care and on disability
	Kasl & Cobb	1966	No	The factor that brought the patient to the doctor need to be connected with the factors that produced the disease
Seeking medical advice for RA or joint symptoms	Kellgren et al.	1953	Yes	Nearly half those with joint symptoms had not sought medical advice. Of those with RA 81% of the males and 62% of the females had consulted doctor. For persons with OA alone, the consulting rate was 12 19% lower than for persons with RA
	Arthritis. Source book	1966	Yes	Increasing number of disability days for arthritis is accompanied by reduction of the proportion under medical supervision
	Helander	1968	Yes	Active patients apply for ADL devices. Twice as many females as males have received ADL devices
Treatment and hospital care	Edström	1944	Yes	47% of invalids with chronic polyarthritis were never hospitalized
	Kellgren et al.	1953	Yes	4% of males and 8% of females with RA were admitted to hospital during five-year period
	Duthie et al.	1955	Yes	Prognosis better if patient is admitted to hospital at an early stage of disease
	Laine & Lettonen	1960	Yes	Medical reasons directed 91% of first hospital admissions but only 60% of re-admissions
	Bjare	1962	Yes	Low numbers of RA patients are treated in acute medical units because beds are occupied by acutely sick patients
	Rask	1963	Yes	Only small part of the patients were severely handicapped because of the hospital' preference for those patients in whom improvement is likely to occur
	WHO-report	1964	Yes	Number of beds (per 1 000 000 population) for care of patients with chronic rheumatic diseases varies from 0 to 175
	Bywaters	1965	Yes	(On indications for corticosteroid treatment). "Cooperative, intelligent patients free from psychological disturbance .. with economic and social obligations"
	Laaksonen	1966	Yes	Cases with juvenile RA in high social class sought medical advice at an earlier stage of disease than did low social class
	Laine	1967	Yes	In some severe cases surgical help was neglected at the same time as some cases with mild disease were operated upon
	Boyle & Buchanan	1968	Yes	Families with two or more RA cases will be over represented in hospital materials which has consequences with respect to conclusions on heredity
Unknown cases of RA	den Oudsten	1960	Yes	92% of cases with definite RA found on survey were already known to the consultation bureau for rheumatic diseases
	Bjare	1967	Yes	40% of persons with RA in an urban community were known to the local rheumatic diseases' dispensary
	den Oudsten et al.	1968	Yes	65% of cases with possible RA found on survey were already known to the rheumatism center

Item	Author	Year	With special reference to RA	Main comment on selection
	Sharp & Keen	1968	Yes	In an average general practice of 2 250 persons, only 44 % (11 cases) of those with RA were estimated to be know to their doctor
	Värmland Health Survey	1968	Yes	92 % (205 persons) of cases with clinically diagnosed RA found on survey of 90 000 persons, were previously known

standards were used for the clinical diagnoses of rheumatoid arthritis

In the US, Cobb et al. were working on the problem of how to identify and define persons with RA by means of a questionnaire (Cobb et al., 1956 Rubin et al., 1956) Cobb & Rosenbaum, 1956). One main conclusion from these studies was that more than one-third of persons with arthritis deny symptoms on questioning, although doctors were having about 20 % more positive answers than were other interviewers.

Criteria of 1956

In 1956 an American Rheumatism Association (ARA) committee, of which Cobb was a member published proposed criteria for RA" (Ropes et al., 1956) 5 of which were obligatory on a diagnosis of definite disease. Three diagnostic categories were identified, namely possible probable, and definite disease. Separate criteria were recommended for the possible group Lowest acceptable time-limit for continuous symptoms of definite disease was 6 weeks.

The basis of the criteria was an analysis of 332 cases of RA from several rheumatologists in the US and Canada. A list of 19 diagnoses, excluding a patient from the RA group was attached. Many of the discussions on problems of criteria are taken up in the said early publication of 1956.

In 1957 the first international conference on population studies in rheumatoid arthritis was held in Bethesda, US, at which five investigations were presented.

Criteria of 1958

In 1958 an ARA committee published a revision of the 1956 criteria for RA (Revision of Diagnostic Criteria for Rheumatoid Arthritis, 1958). The main reason for this revision was that the 1956 criteria were not rigorous enough. Another major change was that a new category classical RA the typical advanced hospital case, was added.

Criteria of 1961

In 1961 the second international symposium on population studies in relation to chronic rheumatic diseases was held in Rome 32 investigations from 1. countries were presented (Kellgren et al. 1963 Kellgren, 1962). The first eight criteria for RA (ARA 1958) were recommended for use in population studies, including a new category Inactive rheumatoid arthritis It was also recommended that the proportion of individuals fulfilling a given number of criteria should be reported so as to give the full gradient of disease. The latter recommendation, however has not been often followed. The exclusions from the criteria underwent only minor changes. The 1961 criteria are presented in Appendix I p. 119

In addition, criteria for ankylosing spondylitis, gout, and non-articular rheumatoid disease were formulated. The construction and application of the criteria have implied an enormous impact on research, not only on population problems but also on clinical work.

Expansion of epidemiological work

In the 1960s the expansion of research on the syndrome of RA continued both in breadth and in depth. Geographical differences (Kellgren, 1966 Lawrence et al., 1966 a) were discussed and Lawrence s cooperation in many surveys in different parts of the world made more precise comparisons possible of the prevalence of single signs and diseases. During the 1960s new materials were collected, e. g. by Bremner (1961) in Great Britain, 858 totally examined in Wensleydale by Burch et al. (1964) 1 102 Blackfeet and 969 Pima Indians (1962–1963) Engel et al. (1966) 1960–1962 a US national sample of 6 672 adults.

The New Haven Study on joint diseases conducted by Acheson (1966) and Acheson et al. (1969) was initiated in 1963. It was designed to measure the relation between certain demographic and socioeconomic variables as related to the distribution of joint disease. Altogether 2 047 persons were included in the sample. Follow-ups of positive cases in investigated populations were also made by e.g., Laine (1962, 1968) and den Oudsten et al. (1968).

Criteria of 1966

In 1966 the third international symposium on population studies of the rheumatic diseases was held in New York. Now 53 investigations from 23 countries were presented (Bennett & Wood, 1968). Broad discussions took place on evaluation and estimation problems of the units—symptoms, signs, and tests—forming the syndrome of RA. A low specificity or sensitivity of the 1961 criteria in some of their applications was recognized. From these discussions, where new data from the Manchester group occupied a central position (Kellgren, 1968 *b*; Lawrence & Wood, 1968) new criteria for RA were constructed (New York Symposium on Population Studies in the Rheumatic Diseases: New Diagnostic Criteria, 1967). The 1966 criteria are presented in Appendix I, p. 119.

The general ideas behind the new 1966 criteria for RA were (*a*) criteria for active unspecific polyarthritis were formed, (*b*) morning stiffness as a criterion for RA was omitted, (*c*) the obligatory localisation of clinical findings to at least one pair of typical peripheral joints together with a fairly simple description of multiple joint pain were introduced as a criterion, (*d*) criteria for X-ray changes and serology were mainly unchanged. The 1961 criteria were thus altered to describe clinical polyarthritis but were only sligthly modified so as not to lose the comparability with earlier investigations.

The criteria from 1966 have been applied in some investigations, and results were presented at the XII International Congress of Rheumatology 1969 in "A Collaborative Review of Diagnostic Criteria", Prague 1969, and by O'Sullivan & Cathcart (1969). It was concluded that the presumed higher specificity of the New York criteria for RA seemed to be true. Considerable observer variance was sometimes present, however. The trend towards interest in the validity and importance of individual criteria rather than in pure prevalence of disease continued and was strengthened.

Climate and arthritis

One aspect that has roused considerable interest has been the proposed low prevalence of RA in subtropical and tropical areas. Many investigations (Shankar, 1968; Kanyerezi, 1969; Blumberg et al., 1961; Shichikawa et al., 1966; Valkenburg et al., 1968; Hijmans et al., 1964; Hall, 1966; and others) have demonstrated the existence of RA in these areas. In, e. g., Jamaica Indians (Lawrence et al., 1966 *c*) and Pima Indians (Burch, 1966) the raw prevalence is even higher than that found in temperate areas.

In Japan (Shichikawa et al., 1966) and Eastern Europe (Lawrence et al., 1969) the prevalence might be low but the main question is "What and how much of prevalence differences is attributable to observer variance?"

In a comparative study of eight investigations Lawrence et al. (1966 *a*) concluded that there was no difference in a prevalence of definite RA between the white, black, or red human race but differences appear in total RA prevalence. Data and discussions from the literature on other aspects will not be dealt with here but will be taken up in connection with data from the study reported in this book.

Previous Swedish investigations

In Sweden three investigations concerning the prevalence of RA have been performed. Edström (1944, 1946) conducted a survey comprising four areas and three towns in different parts of Sweden. The areas were chosen because of their different types of climate. Altogether 72 010 persons were surveyed. The number of *actually* examined persons in different areas and problems of non-response were not clearly reported, as was customary in older investigations. Neither definite criteria for different diseases nor terms used were presented. The examiners, however, were medical students, who had had special training in clinical diagnostic work.

Edström concluded that 7.9 % of the population of Sweden suffered from "rheumatic disease". An essential finding was that 47 % of the chronic polyarthritis invalids were never hospitalized. No difference was found with respect to working ability between those who had and those who had

not been hospitalized. Edström used the terms "acute and chronic" polyarthritis, the latter being equivalent to clinically advanced cases of RA, for which the total prevalence was 0.16% The object of the investigation was to find data on hospital needs for rheumatic patients. In the main, the methodology used, however renders this study mostly historically interesting.

In Hellgrens study of 1963 (1967), mainly directed towards skin diseases, 39 571 persons from five geographically different areas of Sweden were studied. The clinical Rome criteria were applied and, if available, data on X-ray and serology were added. The detailed application of the criteria is unclear however In Northern Sweden (Norrbotten) the prevalence figure for definite and classical RA was 3.4% in Southern Sweden (Kristianstad) ..8% Hellgren reports probable RA in 1.4% possible RA in 1 7% (Norrbotten) and probable RA in 2.5% and possible RA in 2.5% (Kristianstad)· these proportions between classical, definite, probable, and possible diseases are the reverse of those reported by others, e. g. Engel et al. (1966) and de Graaff et al. (1963). In a population, the number of cases with few signs and symptoms of RA, as of any disease, should *exceed* those with a picture of classical disease.

In 1948 Bjure (1957 1967) investigated a community in Central Sweden (Kolsva), where 3 575 inhabitants were examined. Bjure found a RA prevalence of 1.3% for males and 3 1% for females, altogether 79 cases of whom 32 were registered with the local dispensary for rheumatic diseases. A part of this population, 438 persons, were re-investigated in 1967–1968 and the RA prevalence was then 3.0% for males and 7.8% for females (Bjure, 1968). The diagnosis was made on clinical grounds.

General conclusions

The central question of what "RA in population surveys really stands for has been discussed several times by Cobb (1963) and Kellgren (1968 *a* and *b* 1969) and in "WHO Working Group on Epidemiological Studies on Chronic Rheumatoid Arthritis (1966). *One* dilemma is that all arthritides have their mild and incomplete forms. Without knowing the aetiology the boundaries between syndromes will be arbitrary (Wulff, 1969). We are therefore forced to study symptoms, signs, and functional capacity in the population and define them properly to form a pattern of disease instead of diagnostically clear-cut disease entities.

CHAPTER III

An epidemiological survey of RA in Stockholm

Comprehensive presentation of the survey

The planning, methods used, and the completion of the survey are outlined in Figs. 4 5 and 6. Results of examination are presented in Appendix II, Table 1 p. 121. On four occasions in 1965 and 1966 questionnaires with four questions relating to joint symptoms were mailed to persons randomly sampled from four age-groups in Stockholm City

The age-groups, comprising 15 268 persons, were 70–74 56–60, 42–46, and 31–35 years, here referred to as I, II, III, and IV The survey began with the highest and finished with the lowest age group. *Those reporting joint symptoms were* examined first. On the basis of the combinations of answers, the respondents were classified into subgroups with assumed different concentrations of RA cases. The number of data thus collected was increased from age-group I to age-group IV (Fig. 7). To reduce the number of clinically examined persons without losing representativity randomized samples were drawn from some subgroups (Fig. 8). Persons in the symptom-reporting groups fulfilling three or more clinical criteria for RA (Rome, 1961) were personally interviewed

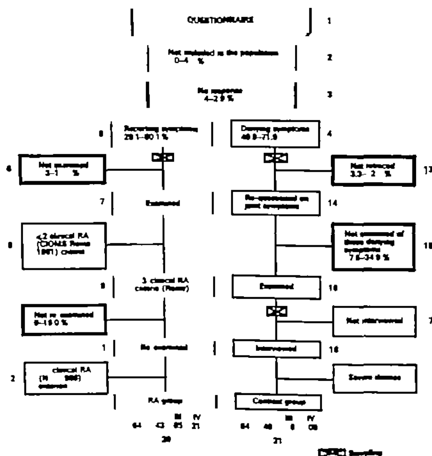


Fig 4. Selection to RA and contrast groups.

Reference list to specified tables, figures, and pages in Fig. 4 on selection to RA and contrast groups.

1 Figs. (p. 21)
2. App. Table 1 (p. 121)
3. App. Table 2 (p. 122)
4. App. Table 1 (p. 121)
5. App. Table 1 (p. 121)
6. App. Table 2 (p. 122)
7 Figure 6 (p. 20)
8. Figure 6 (p. 20)
9 Table 15 (p. 58)
10. App. Table 5 (p. 124)
11 Table 14 (p. 56)
12. App. Table 7 (p. 127)
13. App. Table 4 (p. 123)
14. App. Table 3 (p. 123)
15. App. Table 4 (p. 123)
16. App. Table 3 (p. 123)
17 App. Table 3 (p. 123)
18. App. Table 3 (p. 123)
19 App. Tables 8 (p 127) and 9 (p. 128)
20. P 57
21. P 60

Symptom reporting groups — Symptom denying groups — Re-examination of RA groups

Cumulative percentage of examined in each group

Age Groups: IV 31–35, III 42–46, II 56–60, I 70–74

Examination periods and numbers of examined

Year 1965 1966 1967

Observation period (months) between: Questionnaire and 50 % examined in symptom denying groups — I, II, III, IV

50 % examined in symptom reporting groups and re-examination of RA groups — I, II, III, IV

Fig. 5. Examination periods.

Weighted numbers

Age (years): I 70–74; II 56–60; III 42–46; IV 31–35

Sub-group**: 1, 2, 3*, 5*, Total

*Sampling procedure

Proportion and number of persons fulfilling ≥3 clinical criteria (Rome 1961) for RA

**Based on combination of answers to questionnaire re
1 = Hospitalized for RA
2 = Joint pain, joint swelling and morning stiffness
3 = One or two of joint pain, joint swelling or morning stiffness
5 = Incomplete answers

Fig. 6. Results of examination of groups reporting joint symptoms. Weighted numbers.

Age group	I	II	III	IV
Age during year of screening (yr)	70–74	56–60	42–46	31–35
Born	Jan. 1, 1891–Dec. 31, 1895	Jan. 1 1906–Dec. 31 1909	Jan. 1, 1920–Dec. 31 1924	Jan. 1, 1931–Dec. 31 1935
Date for mailing questionnaire	March 6, 1965	Sep. 23, 1966	Jan. 21 1966	Sep. 6, 1966
Fraction on total population in each age-group in Stockholm City	1/15	1/17	1/13	1/8
Number investigated in each sample	2203	3364	4731	4840
Number drawn in each sample	2136	3369	4775	4839

Reporting symptoms

Denying symptoms II to IV

Serum for serology X-ray film of hands, interview

Serum for serology Interview

EXAMINATION

Questioned on history of polyarthritis

Question "Are your symptoms sensitive to weather?" Yes/No)

Individual criteria for RA (Rome 1961)

Clinical symptoms recorded on joint by joint basis

Data on criteria for RA

Grading of joint swelling 1) absent 2) possible 3) definite

Individual clinical criteria for RA (New York 1966)

Recording of those fulfilling 3 clinical criteria for RA (Rome 1961)

Number of criteria for RA (Rome 1961)

Individual clinical criteria for polyarthritis (New York 1966)

Recording of other joint disorders

Systematic recording of 12 joint disorders

Systematic recording of 30 joint disorders

Systematic recording of several joint disorders

Fig 7 Pertinent data in definitions and examination.

with respect to occupation, housing, sick-care consumption, etc. X-ray examination of their hands and feet was also made and blood samples were taken for serological examination. Functional capacity was assessed in different ways. These preliminary "RA groups" were re-interviewed and re-examined in 1967–1968 for sorting out persons with symptoms and signs not fulfilling the new clinical criteria for RA (New York, 1966). Some new data were collected by personal interviews and most earlier information was brought up to date. Clinical symptoms were then recorded

Questionnaire			Combinations of answers constituting subgroups 1	2	3	4	5
1. Have you at present or have you earlier had joint troubles or rheumatism?				"Yes"		"No"	
2. Have you at present or have you earlier had swelling in one or more joints?				"Yes"	"Yes" to one or two items	"No"	Incompletely answered
3. Do you usually wake up with stiffness in your joints or muscles in the morning				"Yes"		"No"	
4. Have you ever been hospitalized for arthritis?			"Yes"			"No"	
Sampled for examination	Age group	70–74	All	All		1/3	All
		56–60			1/5	1/3	
		42–46			1/3 5	1/7.24	
		31–35			1/5	1/10	

sampling procedure, see text p. 25

Fig 8 Questions, combinations of answers, and sampling fractions.

on a joint-by-joint basis. The final RA group comprised 293 persons (weighted numbers).

Representative samples of those denying symptoms in the questionnaire were examined in the spring of 1967 They were to be used as the basis for contrast groups to the RA groups. The samples were therefore stratified so as to obtain an equal proportion of women in the contrast and the RA groups. Every other woman and every fourth man were drawn in advance for the contrast group. Persons with severe diseases were excluded from the contrast groups. For comparison with the RA groups the contrasts" were interviewed on relevant data. The contrast groups comprised a total of 456 persons.

For both the RA and contrast groups data on income for 1955 1960 and 1965 included spouses and were collected from the taxpayers' register Sick leave data for 1955–1966 were obtained from the local social insurance office. Other data were obtained from the Social Register.

Non-participation in the questionnaire part of the survey was low the maximum being 2.8% As to the examination part, maximum non-participation rate for the symptom-reporting groups was 12% and for the symptom-denying group 35% Several procedures reduced the effect of the non-participation on the final results. A detailed presentation of non-participation rates is found in Appendix II, p. 121

In the final data handling, IBM 360/75 computer and Olivetti Programma 101 were used.

CHAPTER IV

Basic methodological considerations

Pilot study

In 1964 a pilot study on RA epidemiology was performed (Allander & Lövgren, 1964). The objects were to study the following questions.

1 Does a questionnaire on joint symptoms discriminate persons with joint symptoms, especially of RA, to certain groups?

2 Do persons in Stockholm come to a medical examination of joints at a city hospital, irrespective of the distance to the hospital?

The results of the pilot survey showed that the answers to the questions were positive, and therefore some requirements for a large-scale study were fulfilled.

Design of the survey General considerations

Most previous surveys designed to determine the prevalence of RA were made on samples of the whole adult population in an area (reviews by Adler et al., 1967 *a*; Bennett & Wood, 1968). They often resulted in only a few diseased persons in each quinquennial age-group. This also means great difficulties in comparing different ages, because of often large sampling errors, which are seldom mentioned (see p. 26, on Statistical considerations). Further in most previous studies much of the total effort was spent on examining healthy people. An exception in these respects is the study by Adler et al. (1967 *a*). Since RA is a disease with a total prevalence of 1–2 % and this prevalence is highly correlated with age (Wood, 1968), the resources for investigation were concentrated to certain narrowly confined age-groups (Fig. 7). By this design another advantage was achieved. It was possible to change or extend the information in the age-group to be examined in comparison with the previous one. Most valuable time was saved between examinations of the age groups for preliminary analysis of the results and consideration of changes in methods. The similarity between a population survey and a parachute jump—a one-chance undertaking—(Lawrence, XI. Int. Congr Rheum. 1966) was thus eliminated. With this procedure it was therefore possible to fix the methodological changes to a definite time and age-group.

Background for choice of age-group

Age-groups were chosen according to certain generally known facts. In accordance with known prevalence figures in the *age-group 70–74 years* (age-group I) relatively many advanced cases of RA would be found. Symptoms of degenerative joint changes should be common. Occupational activity should be very low Senility would not influence the communication with the respondents in a decisive way The non-response rate is considerable in high age-groups (Frisk et al., 1957).

The next *age-group 56–60 years* (age group II) was chosen because it represents quite a different structure. The prevalence of RA in a population known from other surveys is highest in this age-group (de Graaff et al., 1963). Family and occupational structure is stable and represents an active phase of life without small children. Symptoms of degenerative joint diseases are frequent, but less so than in older age-groups. Arteriosclerotic diseases are relatively few This age-group would be suitable for study of the social consequences of RA, especially as the non-response could be expected to be low

The third *age-group 42–46 years* (age-group III), should have comprised the ages 41–45 Because of unexpected troubles the examination was postponed. In this age-group the prevalence of RA would be half to one-third of that in age-group 56–60. The identification of RA cases in age-group III would be easier because of essentially fewer degenerative joint symptoms. Social structure as to civil status and employment is characterized by stability Non-response can be expected to be low

As regards the youngest *age-group 31–35 years* (age-group IV) sufficiently dependable data

on prevalence were difficult to obtain, even if some guidance could be found in Epstein's et al. (1965) report from the Tecumseh study But supplementary information on the age at onset of RA in hospital series could be used and has been published, e. g. by Lowman (1958). The prevalence was estimated to fall by 1 %–0.5 %. The influence of degenerative joint disease should be insignificant. It could be foreseen that fairly few cases would be found within the limits of available resources. It was judged as unwise to abandon the method used in other age-groups. The age-group 31–35 was also used in a prospective study on joint symptoms and diseases. Mainly because of changes of domicile in this age-group nonresponse could be predicted to exceed that of age groups II and III.

Definition of population

A random sample of each age-group (Fig. 7 p. 21) was drawn from the tape-recorded population register of Stockholm City Samples were drawn only a couple of weeks before mailing the questionnaires to the respective age-group. In spite of this precaution, some information on the tape was not up to date. In age-group 70–74 a comparatively large number of dead, were still recorded on the tape.

For inclusion in the survey two conditions had to be fulfilled:

(*a*) The respondent had to be registered on the official census tape

(*b*) The respondent had to be actually residing in Stockholm City on the date for the mailing of the questionnaire.

As a consequence of these two conditions, persons living in the city but not officially registered there were not included. This group is small and does not influence the results. Another consequence was that people officially registered as Stockholm citizens but actually having a permanent residence outside the City were excluded. Those who had moved from the area before date of mailing the questionnaire are correctly excluded and therefore represent no loss of information. On the other hand, the small but not exactly defined group of persons that lived within Stockholm City on a certain date without being officially registered there represented a loss of information. Of those who moved into the City in 1965 about three quarters were 29 years old or younger (Statistical Year-book of Stockholm 1966). The influence of this group on the total RA prevalence will thus be insignificant.

Sequence between age-groups

Since some of the difficulties of a survey including older people were familiar to the writer and the prevalence of RA in the oldest age-group would be relatively high, it was decided to start with age-group I, 70–74 years. The number of standardized recordings of medical data was small but non-standardized data were collected for application in standardized form in later age-groups. The sequence between age-groups, cumulative numbers of examined and other pertinent data are presented in Figs. 5 and 7 p. 20–21

Statistical considerations

Sampling

With the sampling procedure used (two-phase sample) individuals were classified into subgroups according to combinations of answers. In subgroups 1 and 2 *everybody* was chosen for medical examination. In subgroups 3 4 and 5 sampling was performed according to expectations about the prevalence of RA and available resources (see Fig. 8, p. 21) Special problems arose in subgroups 3 and 5 of age-group 70–74 because of an initially not exact separation of subgroups. *However it was later possible to* reconstruct sampling fractions for every individual (Table 2). The slight differences between weighted numbers of examined and numbers really drawn are seen in Fig. 7 p. 21 These differences are partly due to errors in the computor data processing and were impossible to locate exactly without great effort. These errors are of no significance in the final results.

The aim of sampling in the symptom-denying groups was to obtain a fixed number of individuals in accordance with available resources. Therefore, sampling fraction, as for age-group 42–46, was not a simple fraction.

Sampling errors when estimating proportions of individuals with RA in the present survey

Indicate with n_H the number of individuals in the first phase sample, classified to stratum no. H and with n the sum Σ_H over all strata.

Indicate with n^1_H those who in the respective group underwent medical examination and with m_H the number of those with RA. Then the weighting number is $W_H = n_H/n$ and the estimated proportion of individuals in every subgroup $p_H = m_H/n^1_H$. The estimate of proportions will be $p = W_H p_H$ and an estimate of the standard error will be

$$s(p) = \sqrt{W_H^2 \frac{p_H(1-p_H)}{n_H^1} + \frac{1}{n} W_H (p_H - p)^2}$$

This will result in the following estimates of confidence intervals for total RA prevalence with 95 % confidence in the respective age-group:

Age-group	Males	Females	Total
70–74	1.7 ± 1.0	5.8 ± 1.4	4.3 ± 1.0
56–60	2.7 ± 1 4	6.3 ± 1.6	4.9 ± 1 1
42–46	0.7 0–1.1	2.8 ± 1.1	1.8 ± 0.6
31–35	0.3 0–0 6	0.6 0–1 1	0.5 0–0.8

Interval 0–1 1 % indicates that the true value is less than 1 1 % with 95 % confidence limit.

These calculations do not take into account the effect of non-response and measurement errors. Differentiated prevalence figures will be found in Table 15 p 58.

The error problem in estimates of small proportions within a population

Estimation of small proportions is often the aim of population studies within medicine, e. g. the estimate of the proportion with a certain uncommon handicap. As expenses and doctor's time are *limited in a project, the number of individual* medical examinations is limited and only a small number of handicapped individuals will be found when the *whole* population is examined.

In addition to shortcomings of diagnostic procedures, errors due to *sampling* and *non-response* will appear

Sampling errors in estimates of proportions will often be quite considerable. However if sampling is performed randomly these errors will be measurable.

Non-response errors depend upon the proportion of handicapped in the non-response group compared with that in the response group. It will be demonstrated here that the effect of non-response might be considerable.

Table 2. *Persons in different sampling fractions in the RA group*

Age-group Years ..	I 70–74		II 56–60		III 42–46		IV 31–35		Total	
Sex	M	F	M	F	M	F	M	F	Unweighted	Weighted
Not weighted	7	47	22	91	9	28	6	10	220	220
Weighting number										
2	—	1	—	—	—	—	—	—	1	2
3	1	—	—	—	1	3	—	—	5	15
4	—	—	—	—	—	4	—	—	4	16
5	—	1	2	4	—	—	—	1	8	40
Total										
Not weighted	8	49	24	95	10	35	6	11	238	
Weighted	10	54	32	111	12	53	6	15		293

Errors in simple random samples

Assume that we have at our disposal a sample of n individuals from a population, obtained through simple random sampling. We neglect errors in measurement and non-response and observe a proportion (in %) $p = m/n$ 100 (m = number of individuals with handicap). How reliable is p as an estimate of the true prevalence P in the population? It is customary to form a confidence interval $p \pm I$ which covers the true value of P with a certain confidence, e. g. 95 %

Table 3 shows confidence intervals for different sizes of n and observed proportions with handicap (p). It will be seen that sampling errors in estimating small proportions are great, even in reasonably large samples. In Adler's et al. study (1967 *a*) 26 epidemiological surveys on RA are comprehensively reviewed. In 66 % of the studies the examined samples did not exceed 600 persons. Results of many population studies are therefore impaired by large sampling errors, although these are seldom mentioned.

In reducing sampling errors, phase-sampling techniques are possible. As early as 1938 Neyman published a report on the theory of two-phase sampling in human populations. In spite of a considerable reduction of numbers of examined, the possibility of a representative description of the population is maintained (Dalenius, 1968). On a large first-phase sample a non-expensive method of measurement is used for classifying into subgroups (substratification) in such a way that the differences in proportions of handicapped between the groups will be as great as possible. The next step is a second sampling from each subgroup. Medical examination is then performed in each subgroup. In groups with a high proportion of handicapped no subsampling might be necessary

This method was applied in the present study The first phase comprised screening by mail questionnaire with four questions on joint symptoms. A substratification was then performed according to the different combinations of answers (Fig. 8, p. 21)

Table 3. *Confidence intervals for true prevalence rates for different observed prevalence percentages and different sample sizes in simple random samples*

Observed prevalence, %

Sample size	1%	2%	3%	4%	5%	6%
100	–4.0	0.2–3.8	0.5–7.3	1.0–8.8	1.5–10.2	2.1–11.6
400	0.2–2.2	0.8–3.6	1.5–5.0	2.2–6.2	3.0–7.4	3.8–8.5
900	0.4–1.8	1.2–3.1	2.0–4.3	2.8–5.4	3.6–6.6	4.5–7.7
1 600	0.5–1.5	1.4–2.8	2.2–3.9	3.1–5.1	3.9–6.1	4.9–7.2
2 500	0.6–1.4	1.5–2.6	2.3–3.7	3.2–4.8	4.1–6.0	5.1–6.9
3 600	0.7–1.3	1.6–2.5	2.4–3.6	3.4–4.7	4.3–5.7	5.3–6.8

Effect of non-response errors

In surveys of this kind, non-response cannot be totally avoided, even if a meticulous planning of the use of resources for non-response follow-up might greatly reduce this group. Non-response rates of different groups in the present survey are analyzed in Appendix II, p. 121. This follow-up is very important, as the following example will show.

Assume that non-response is 6% and the observed prevalence of a particular handicap is p% ($p = m_a/n$). Hypothetical extremes are:

1. None of the non-respondents has the handicap: this results in the *minimum estimate* p%.

2. All the non-respondents are handicapped, this results in the *maximum estimate* $p + 6$%.

As p is a small number (e. g. 5%) and the non-response rate is bigger than p, this will imply an obvious uncertainty.

One is therefore left to make a subjective judgement of the characteristics of the non-respondents.

Often the not outspoken assumption is made *that there is no difference with respect to handicap* between respondents and non-respondents. The estimate of the unknown proportion P will be

$$p = \frac{m_a}{n - n_a}$$

n_a = number of non-respondents;

m_a number of observed respondents with handicap.

There are, however strong reasons to assume that the non-respondents would have other characteristics, even if the extremes, none or all with handicap can be ruled out. The alternative is to set *subjective limits for proportions of handicapped* in the non-response group.

If there are reasons to assume that the prevalence is higher among the non-respondents, an upper limit for prevalence in the non-response group might be set.

An example: The non-response rate is 5%. The estimated proportion among respondents is $p = 3.5$%. The upper limit for the proportion of handicapped among non-respondents is estimated at 15%. Then the upper limit for the proportion of handicapped in the whole population is $p = 0.95 \times 3.5 + 0.05 \times 15 = 4.1$%. Sampling errors and confidence intervals are then calculated on the basis of this *upper* border of error.

Other statistical methods

The comparison of frequencies was made by the χ^2-test with Yates' Correction (Ferguson, 1966). The correction decreases linearly with increasing expected frequency in the interval 5 to 20.

The correlation coefficients refer to linear correlation.

The multiple linear regression analysis was made by the techniques devised by Råde (1962).

In a few instances was calculated to best inter relationship (Goodman & Kruskall, 1963).

The following levels of significance were used to indicate the probability p

$0.01 < p < 0.05$

** $0.001 < p < 0.01$

*** $p < 0.001$

Methods for collection of information

Physical examination

Examinations were made at St. Erik Hospital, where different accommodations were available. Only relatively few persons were examined in their homes or elsewhere. Persons were called to the hospital by telephone. In every age-group those who reported previous hospitalization for RA were examined first. All were examined by the author with the exception of approximately 100 in age-group 70–74 who were examined by *O. Lövgren, M.D*

The examination started with repetition of the four questions on joint symptoms (see p. 34). Changes in answers were recorded and certain history data on those answering positively were collected by a free interview For common past and present symptoms and/or diseases of the locomotor system, fixed criteria had been prepared in advance. The number of symptoms and/or diseases classified by such fixed criteria was increased from age-group I through IV and contrast groups. These diseases and symptoms will not be considered in detail here.

If the examinee mentioned symptoms or disease involving certain joints, these were examined first. Findings forming the basis for recording were pain on motion, tenderness, swelling, and limitation of movement, according to the Rome clinical criteria 1961

An analysis of the implication of each of these parameters and their definition in this investigation will be found in chapters IX–XII.

All the persons were also asked whether they suffered from long-standing diseases or symptoms involving sites other than the joints. Easily diagnosed diseases were recorded, though not systematically and as regards information in this respect, reservation must be made for incompleteness. In age-group II and onwards clear-cut cases of psoriasis involving the extremities were systematically recorded. Fig. 7 p 21 shows pertinent data from examinations of different groups.

Examination of joints. Blood sampling

The joints were examined mainly in accordance with current principles of clinical practice, e.g. Beetham et al. (1965). The examination was standardized. Some notes on the examination of special joints will be found in Appendix VI, p. 134 If limitation of movements or pain on movements were present, a history was taken on symptoms referable to that particular joint.

Those who on physical examination were found to fulfill three or more clinical Rome criteria underwent a comprehensive physical investigation with medical history taking. The following data were recorded. Steinbrocker functional class, the respondent's opinion of which was his worse joint and the examiner's initial decision as to operability of hands (Bäckdahl, personal communication 1965) or knees (Waldius, personal communication 1965). A blood sample was drawn to assess rheumatoid factor by SSCT (Sensitized Sheep Cell Test) and AFT (Acryl Fixation Test). The erythrocyte-sedimentation rate was measured.

First interview with RA group

At the screening procedure an appointment for interview was made with every person fulfilling three or more clinical Rome criteria. The interview form is presented in Appendix III, p. 129 It contains data on occupations and education, basic data on clinical history including hospitalizations, and present medical care. Housing conditions were also considered. The interviews were made by a female clerk with clinical RA, Steinbrocker stage III, and a nurse with fairly small residual RA changes and with no active disease, Steinbrocker stage I–II. They were working with the project from start to end. The interview form was designed in close cooperation with the statistician of the survey and with assistant statistician D. v Sydow at that time working at the Central Bureau of Statistics.

Re-examination of the RA group

General considerations

The introduction of the New York criteria of 1966 placed the survey in a new and, from some viewpoints, favourable situation. It then became possible to apply the new 1966 criteria in age-group 31–35 years and at examination of those groups on a joint-by-joint basis. As the RA criteria from 1966 were stricter than those from 1961 it was decided to re-examine the screened RA group. This re-examination took place over the period November 1967–January 1968. Six main *advantages* were thus achieved.

(*a*) The RA group was cleared from persons who did not have long-standing joint symptoms of RA type;

(*b*) Comparability between two sets of criteria was achieved

(*c*) The influence of time on certain criteria could be estimated

(*d*) The recording of joint findings on a joint-by-joint basis allowed an analysis of the joint pattern

(*e*) An up-dating of earlier data was possible;

(*f*) Certain additional interview information could be obtained.

Some *disadvantages* of the re-examination were also recognized.

(*a*) The time of observation was relatively long, 18–33 months, which made the definition of age used in the investigation less strict. The interval between clinical observations and interviews for the RA and the contrast group was maximally 10 months,

(*b*) Radiographic and serological data on the RA group were mostly collected in close connection with the first interview. In many cases a long time elapsed between these procedures and the physical examinations. It was not possible to take new X-ray pictures and to draw new blood-samples in every RA person,

(*c*) Another drawback of a re-examination would be a new non-response group.

Main contents of re-examination form

The re-examination form is presented in Appendix IV p. 131

It contained data on joint and clinical findings with emphasis on changes of RA nature. On the basis of information from the interviews and examinations, the needs for medical care were assessed. The respondents were asked about their rheumatic complaints. Additional questions were asked concerning occupation, sick care, social welfare consumption, and housing. As pain is the most prominent feature of RA, data for an analysis of the comprehension of pain were collected.

Height and weight were recorded, using Stathmos person scales.

In most RA-patient materials RA *alone* is considered. Diseases other than RA were also systematically recorded, using clinical diagnoses and autodiagnoses as a basis. Information in this respect gave some information of the magnitude of the impact of other diseases on RA persons.

Radiological data

X-ray films of hands, wrists, and feet were taken in the X-ray department of St. Erik hospital. Film size 17 × 24 cm, CEA film, exposure data 45 KV 50 mA, exposure time 1 second.

X-ray films were read at two main sessions knowing only age and sex of the individual. Professor Laine, Heinola, with experience of X ray film readings together with Lawrence et al. (1961), kindly read the films of the first 100 examined persons together with the writer after an initial reading by the writer alone. Data were recorded on a joint-by-joint basis. When, according to Laine, acceptable agreement on interpretation of single data was reached, the rest of the films were read by the writer alone as were also the Heinola batch of films. A graded classification of X-rays for RA include a vast number of information units and combination of units which only to some extent could be covered by a scheme.

A grading for RA was constructed mainly on the basis of the work by Lawrence (1965), Kellgren & Lawrence (1957 *a*) and Engel et al. (1966) and of discussions with Laine. The grading applied is found in Table 4, p. 30. Intratarsal and tarsometacarpal joints were not included in this scheme because of general difficulties in evaluating changes in these joints with the X-ray projection used. When interpretable, findings were classified as in the CMC joints.

Grading of erosions

By drawing conclusions from the discussions on p. 51 the following grading for erosions was applied.

Table 4 *X-ray grading for RA*

Hands and feet. Minimum requirements

		Grade 1	2	3	4	0
Grading of erosions	1	Single erosions in RC, IC, CMC, MCP PIP MTP	Two erosions in RC, IC, CMC, MCP PIP MTP DIP or			Single erosions in MTP I or <2 erosions in DIPs only
	2		Single erosions in RC, IC, CMC, MCP PIP MTP	Four erosions in RC, IC, CMC, MCP PIP MTP		2 5 erosions limited to PIPs only (Bouchard) Single erosions in MTP I
	3		or Single erosions in RC, IC, CMC, MCP PIP MTP	or Three erosions in RC, IC, CMC, MCP PIP MTP		Single erosions in MTP I or DIP I
Reduction of joint space		Present in at least one joint				
Ankylosis					In at least one joint	DIP IV V feet
Comments			Erosions in DIP accepted only in combination with erosions above	Single erosions of grade 3 in RC, IC, CMC, MCP PIP qualifies if two erosions of grade 1 or 2 are present in other joints		

Grade 1 Single small but definite erosion.

Grade 2 Two small erosions or one medium-sized erosion.

Grade 3 Three small erosions or one or two medium-sized erosions (grade 3 Engel et al. 1966).

Grade 4 Definite multiple fairly large erosive destructions (grade 4 Engel et al. 1966).

Grade 5 Severe erosive changes totally or almost totally destroying joint structure.

Grading of osteoarthrosis was not made. Only presence or absence was stated mainly according to Kellgren & Lawrence (1957 *b*) using grade 2 or more as present" Localization of erosions to certain groups was weighted as to minimum severity gradient of radiological RA.

Serological methods

A 5 ml blood specimen was drawn at the first contact with those fulfilling three or more Rome criteria for RA. Blood specimens were also drawn from the contrast group and from a random sample of those reporting joint complaints in age-group IV 31–35 years. No additives were used. The blood samples were mailed to the National Bacteriological Laboratory where serum was collected and frozen. The way from patient to freezing was therefore equivalent to the routine in handling of such blood samples. Because of loss of some samples and a few instances of haemolysis, new blood samples were drawn at re-examination. Serum samples were preserved at −20 C. Tests applied were AFT and SSCT Accessory data are found in Appendix VII, p. 135

Examination of those denying joint symptoms

The routines used in physical examination of this group were identical with those applied to age-group IV of RA (see Fig. 7 p. 21). For a closer study of joint symptoms and diseases missed by the questionnaire, those who had primarily denyed all joint symptoms were interviewed by telephone. Questions were made on joint symptoms in specified sites. The respondent was asked to appear for examination at the hospital. At the examination those who had been sampled in advance for the contrast group were interviewed on items indicated by bold faced figures on the first and second interview forms used for the RA group (Appendix III and IV p. 129 and p. 131). These interviews were made by four persons plus the author Interviews were discussed with the author immediately after their completion, so as to achieve a fair amount of exactness and uniformity in the interpretations of answers.

Need of ADL devices

At re-examination the RA respondents were questioned on their possession and need of ADL (Activities of daily living) devices. Every respondent was offered free and quick provision of individual ADL devices, including testing of needs and advice for use (see Appendix VIII, p. 136).

Functional capacity

General principles

Thelius (1969) presented a survey of reports on clinical methods for the assessment of inflammatory activity and functional capacity in patients with RA. Thelius conclusion was that "numerous criteria are based on the patient's or on the examiner's subjective opinion concerning the condition, while proportionately little attention is paid to the patient's functional capacity" This holds true also for RA prevalence studies.

As one of the main objects of the Stockholm survey was to measure the influence of disability on everyday life of rheumatics, detailed objective laboratory functional testing was discarded as a general method. It was also considered that subjectivity would be inevitable even in "objective" tests such as grip strength and walking time. The influence of pain on function was emphasized by Moritz (1967). For this reason the conventional grip-strength method, using a tourniquet, was not applied. The fact is that a sick person achieves relative compensation for a certain impaired function by using more time on it than does a healthy person. Another reason was that a population survey will detect relatively many RA persons with only slight or moderate disability

Moreover the Stockholm survey was designed to study the effect of disability on the individual and the group. Primarily it was not directed towards individual rehabilitation and vocational training.

Most studies concerning problems of the function of RA persons and the activity of the disease have been reported in connection with therapeutic trials (e. g. Lansbury 1964). One approach to these problems is represented by Swanson et al. (1968) who give detailed schemes for recording joint angles. Personally I do not find it very fruitful to comprehend a sick person as an isolated machine, because this way of thinking pays little or no attention to the importance in the patient's social function and condition. Although considered both subjective and gross, Steinbrocker's et al. (1949) grading of functional capacity was used, because it is the most widely accepted measure of describing the functional capacity of RA patients.

Lowman (1958) described and analyzed disabled patients by means of an index of 106 activities of daily living, and the same method was used by Flatt (Rheumatoid hand research project). It was felt that their way of measuring disability would best serve the purpose of the present investigation.

Present survey

Functional capacity was intended to be *one of several* measures of the effect of RA on the joint system.

The individual functions tested are presented in Appendix V p. 133

For several of the functions, e. g. managing safety-pins and table knives, standard devices were used. Functional capacity was thus investigated at the first interview and later on re-tested by the writer on re-examination at the second interview

By chosing functions that were uniform for both sexes, an imbalance with respect to household activities was avoided.

The chosen functions were also pure arm, hand, and leg functions.

The number of functions investigated by tests or questioning was 17 for arms–hands and 9 for legs.

A four-step grading was applied for every function, the scoring for "without appreciable difficulty" was 0 and for unable to manage it was 8. A gravely impaired function was thus given more weight.

Data from official sources

Sick-leave data

Data on sick leave for the RA and contrast groups were obtained from the Stockholm City Social Insurance Office. These data covered three periods: 1955–1958, 1959–1962, and 1963–1966. Details will be found in Appendix IX, p 137

Information on income

One of the objects of the investigation was to estimate the effect on income of long-term dis-

case exemplified by RA. To cover an income development primarily for groups and secondarily for individuals, "taxable income for national income-tax levy" was chosen as a measure. This information was collected for the respondent and spouse for the years 1955 1960, and 1965 Details will be found in Appendix IX, p. 137

Social welfare

Information as to whether a person had received social assistance between January 1965 and September 1967 was collected from the register of the Social Welfare Committee. This implies a crude measure of the nowadays widely differentiated social welfare. A detailed study of this aspect was judged to fall outside the scope of the present investigation.

Screening instrument. Questionnaire

Earlier investigations

RA implies symptoms that admit some grade of autodiagnosis. It is therefore reasonable to assume that positive answers to questions on joint symptoms would concentrate RA cases. As joint symptoms are common, however true positive rates of answers relating to RA would be low

Cobb's questions (Rubin et al., 1956), now widely used in epidemiology of joint diseases, showed their ability to concentrate cases of classical plus possible RA. One of the questions, "Do you wake up with stiffness or aching in your joints and muscles?" is accepted as criterion no. 1 for active polyarthritis (Bennett & Wood, 1968). Cobb and his collaborators have applied their questions as an *interview* measure on RA (Cobb & Kasl, 1966). These questions, however definitely measure a joint syndrome other than that conventionally regarded as RA (Kellgren, 1968) as was confirmed in the present study (see p. 36 on the function of the screening instruments).

Table 5 summarizes surveys by interviews and/or questionnaires on joint symptoms. Out of eleven surveys using questions as a screening instrument, only three (Adler et al., 1967 *a* Cobb et al., 1956 Gill, 1968) also investigated samples of those *denying* joint symptoms. In six of the 19 surveys information on total joint-complaint rate is lacking. Joint-complaint rate is generally high but varies and figures are difficult to compare.

Accordingly only a few authors have used interviews and questionnaires as a screening instrument for concentrating persons with joint symptoms to certain groups in order to reduce the number of examined and yet preserve representativity

Questioning on joint symptoms. Some recognized problems

Some investigators have noticed drawbacks and imperfectness of questionnaire answers in the field of joint symptoms. Gill (1968) who found that out of 462 females answering positively to Cobb's questions, 80 had misunderstood them. Elinson & Trussel (1957) noticed that the average person reported only half the bone and joint diseases occurring in his family Lawrence (1960) noted that if the same interviewer re-questioned a population on joint symptoms, the proportion reporting symptoms rose from 40% to 54% On the other hand, Collen et al. (1969), using re-questioning by questionnaire in 2 352 persons, found the reverse, namely a lower proportion reporting symptoms. On re-questioning, "Have you had any bad arthritis or rheumatism of the joints in the past year?" 25% changed from "Yes" to "No" and only a few from "No to "Yes Cobb et al. (1956) and Cobb et al. (1957 *a*) reported that more than one-third of those with classical arthritis" denied symptoms on questions irrespective of who asked the questions. They also found great differences between proportions in the same population answering in the affirmative a question by questionnaire and by interview Kellgren & Lawrence (1956), collecting information for the Leigh study reported considerable inconsistency in positive answers to questions on morning stiffness. Only 74 (63%) out of 118 gave the same answer to the same question in two interviews. Cobb & Rosenbaum (1956) found that doctors obtain some 20% more positive answers to questions on joint pain than do lay interviewers but that false-positive as well as false-negative answers were obtained. Cobb et al. (1956) and Acheson et al. (1969) pointed out that different prevalence figures on joint symptoms might be the effect of different sequence between questions and examination.

In conclusion, data show that persons with joint symptoms can be concentrated to certain groups by using a questionnaire. This concentration is, however not at all perfect. The meaning of *an individual* answer to questions on joint symptoms is highly uncertain. A questionnaire will thus function as a screening instrument applied to *a*

Table 5 *Some surveys using interview or questionnaire information on joint symptoms*

Author	Year	No. of persons investigated	Age-group	Using screening procedure: No	Yes. Negatives medically examined: Yes	N	Joint-complaint rate
Edström	1944	48 160	All			+	?
Kellgren et al.	1953	3 515	15+			+	40%
de Blécourt	1954	3 378	14+			+	13.5% males 21.7% females
Cobb et al.	1956	1 323	15+		+		21.8%
Kellgren & Lawrence	1956	537	55–64	+			?
Feldman et al.	1958	678	10+	+			17 „ males 26% females
Miall et al.	1958	24 343	15+			+	?
Arthritis and Rheumatism reported in interviews Wash. Publ. Health Serv Publ. 584 B. 20	1960	235 000	All	+			55–64 years 34% males 23 „ females
de Graaff	1960	141 845	15–64			+	?
Bremner	1961	1 821	15+			+	?
Laine	1962	539	15+	+			30% males 63 females
Mikkelsen et al.	1963	7 207	6+	+			34.4% males 34.8% females
Engel et al.	1966	6 672	18–79	+			?
Shichikawa et al.	1966	5 019	All			+	10–12 (two areas)
Adler et al.	1967	6 760	20+		+		42.6%
Adler & Abramson	1968						
Gill	1968	3 014	Females. Majority between 20–30 yrs.		+		15.3 „
den Oudsten et al.	1968	414	Females 50–59			+	37%
Acheson et al.	1969	2 199	21+	+			35–64 years 23.5% males 41% females
Wagenhäuser	1969	819	15+	+			72.9%

group but not to *an individual*. Therefore, questions made to groups for screening purposes can probably be unsophistically formulated. For individual use, however a more precise wording is unavoidable. Acheson et al. (1969), noticed that "arthritis" by the layman was defined as a combination of pain, stiffness, and swelling and "rheumatism" as nightly joint pain. The vagueness of the terms "arthritis and rheumatism" as used by the layman, is generally recognized.

Screening questions used in the present survey

Cobb's version and the Swedish questions as actually used in this survey and as translated into English will be given as a basis for the discussion.

Question 1

(Cobb) Have you ever had arthritis or rheumatism?

Har ni för närvarande eller har Ni tidigare haft ledbesvär eller reumatism?

Have you at present or have you earlier had joint troubles or rheumatism?

Question 2

(Cobb) Have you ever had swelling in any joints?

Har Ni för närvarande eller har Ni tidigare haft svullnad av någon eller några leder?

Have you at present or have you earlier had swelling in one or more joints?

Question 3

(Cobb) Do you wake up with stiffness or aching in your joints or muscles?

Brukar NI vara stel i leder eller muskler när N vaknar på morgnarna?

Do you usually wake up with stiffness in your joints or muscles in the morning?

Question 4

(Cobb) ---

Har NI någon gång legat intagen på sjukhus för ledgångsreumatism?

Have you ever been hospitalized for rheumatoid arthritis?

On all four questions "Yes" or "No" were the alternatives to be marked in pencil.

The wording of the applied questions is not identical with Cobb's version. A direct translation of Cobb's question is not possible. The word arthritis is in Swedish more exactly translated into "ledinflammation" (English: joint inflammation"). This Swedish word is hardly used in everyday speech. A better Swedish word for arthritis" is "ledbesvär" (English: "joint trouble"). The short English word ever" is equivalent to the Swedish word någonsin or more clearly nu eller tidigare (English: now or earlier"). The word rheumatism has probably about the same meaning in English and Swedish—a broad spectrum of joint or muscle symptoms of various sites. Cobb's wording any joints was in Swedish preferred to be more exactly defined, mentioning both single and multiple joint swelling (Sw svullnad i någon eller några leder").

Concerning Item 3 Cobb's wording is wake up with stiffness or aching As aching implies a painful experience and a more pure conception of stiffness was desirable, aching" (Swedish: värk") was left out.

As the area of miscomprehension within different pain descriptions proved to be considerable (see p. 45), the exclusion of aching" in Item 3 was an advantage with respect to precision.

On the questionnaire no time limit was stated for morning stiffness in age-groups I and II, but in III and IV one hour was given as minimum duration. This means that a theoretical reduction of the proportion of those actually having morning stiffness occurs in age-groups III and IV in comparison with age-groups I and II.

However on *examination* the one-hour duration of morning stiffness was applied as the qualification limit for all age-groups. A narrow lower limit, as e.g. 15 minutes, recommended in the *1966* criteria for polyarthritis, was considered to be inadequate and to include too much poorly defined stiffness.

In Item 4 the Swedish common word for rheumatoid arthritis, "ledgångsreumatism" literal translation *joint rheumatism* was used for the purpose of concentrating to a special group persons hospitalized for RA.

In age-group I, 70–74 years, the wording was (Swedish: vårdats på sjukhus för ") literal *translation* been treated at hospital for It was found that with this wording fairly many of those who answered positively in this group took it to mean outpatient as well as inpatient care. The wording was then changed into varit intagen på sjukhus för " been an inpatient for

The various problems of interpretation of questions and of translation to achieve international comparability have received fairly little attention in rheumatology However O'Brien et al. (1968), proposed that the lower prevalence of rheumatism in social class I than in social class V was more likely to be due to the ability of the respondents to interpret the questions than to the epidemiology of the rheumatic diseases" Harris (1968) mentioned that patients tend to confuse stiffness, pain and limitation of movement " Hall (1966) *pointed out that there* were considerable difficulties using the criteria in an African population a history of morning stiffness is almost impossible for a stranger to evaluate. Abramson et al. (1964), in reporting on their Israel survey stressed, that for laymen as for many doctors, the literal Hebrew translation of arthritis means rheumatic fever Bremner et al. (1968) found much less rheumatic complaints in a Jamaican population. They suggested that difficulties in communication could have been responsible for this low complaint prevalence.

In conclusion it can be stated that:

1 A question used *in a self administered questionnaire for group* screening purposes does not require any subtle formulation

2 For *individual* screening the wording must be as exact as possible

3 The same exact and thus more complicated question might therefore be used both for

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Har Ni för närvarande eller har Ni tidigare haft svullnad av någon eller några leder?

Have you at present or have you earlier had swelling in one or more joints?

ncomplete answers or admitting one or two ymptoms. However 75.2 % (245 of 326) of the rsons with rheumatoid arthritis were found in ubgroup 1 (been hospitalized) and subgroup 2 three clinical symptoms) comprising only 14.2 % 1 719 out of 12 136, weighted numbers) of the otal numbers of examined persons.

The capacity of the screening instrument to concentrate persons with RA, can therefore be udged as good.

Differences between RA patients in subgroup 1 (stating hospitalization) and subgroup 2 (stating three clinical joint symptoms)

A greater part of those with an advanced form of the disease were concentrated in subgroup 1 than in subgroup 2. The proportions of total rheumatics in subgroups 1 and 2 with certain clinical, laboratory social, and hospital consumption data are presented in Figs. 9 and 10. The figures refer to the toal number of rheumatics found at the first examination and ranges are illustrated.

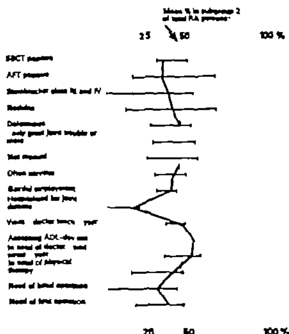


Fig. 10 Percentage in subgroup 2 (reporting three clinical symptoms) of RA persons of total with certain clinical and anamnestic findings (data refer to first examination). Bars indicate ranges.

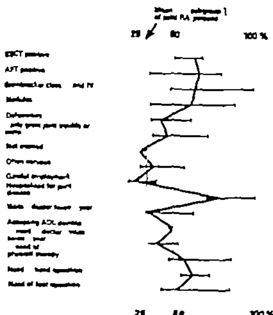


Fig. 9 Percentage in subgroup 1 (reporting hospitalization) of RA persons of total with certain clinical and anamnestic findings (data refer to first examination). Bars indicate ranges.

In subgroup 1 which includes an average of 30.8 % of the total number of RA persons, were found 62.7–64.4 % of those with positive SSCT or AFT. As regards incapacitated persons of Steinbrocker functional classes III and IV 62.2 % were found in this group as were 58.6 % of those needing hand operations. This does not mean that persons with certain social parameters (divorced and unmarried, often nervous, or gainfully employed) were concentrated, but their proportions were the same as for the group as a whole.

In subgroup 2 the average RA person is healthier as will be seen from Fig. 9 yet 37.8 % of the rheumatics with Steinbrocker functional classes III and IV and 35.5 % and 33.9 % of the seropositive cases (SSCT and AFT respectively) are found in this groups. It should be noted that a narrow majority of those needing ADL aids (5..8 %) and those in need of outpatient care twice or more times in year (51 7 %) are found in subgroup 2. It is also remarkable that 15 7 % of those who in the questionnaire denied that they had been hospitalized for joint disease admitted such care in the later interview

Table 7 *Proportions and numbers healthy at examination of those reporting joint symptoms*
Weighted numbers

Sex	M		F	
	No	%	No.	%
Age-group				
I	40	*13.3*	29	*4.6*
II	123	*21.0*	113	*11.6*
III	140	*22.1*	193	*20.2*
IV	86	*18.1*	145	*19.4*

% of examined in each age-group.

Healthy persons among those giving positive answers on joint symptoms

In some of those who, in every age-group, primarily stated joint symptoms, no diagnosis was established at examination. This holds true both for joint diseases and for some internal disorders which to the layman may appear as joint diseases, e. g. ankle oedema or acromegaly. This proportion varies from 4.6% of the women in the oldest age-group to 22.1% of the men in age-group III (*Table 7*).

Joint symptoms in the group denying symptoms

*Joint symptoms were in this group generally re*corded with greater exactness than in the previous age-groups I–III as will be seen from Fig. 7 p. 21 in the chapter on Methodology. In diagnosing 53 joint symptoms or diseases, it was presumed that *an average person reasonably would have re*ported them in the first questionnaire. Pain limitation of movement, and different kinds of swelling were therefore the three essential diagnostic data. Different types of "wrong answers" can be expected in this group. Firstly the observation time must be taken into account. From 8 to 27 months elapsed between the mailing of the questionnaire and the examination. By *requestioning* those diseases or symptoms which existed *before* answering the questionnaire could be fairly well defined as regards time. The proportion of such "wrong" answers in the questionnaire was in all these age-groups greatest in men and varied between *18.5%* and *33.3%* of the total number of diagnoses in the respective age-group. For women *the corresponding figures were 13.8% and 24.3%*. It is remarkable that the proportion of wrong answers was high in the youngest age-group, although the number of total diagnoses was low.

The "wrong-answer persons" often said, "Yes, *certainly I have had some joint trouble for several* years but I did not think that was what you wanted to know". The questionnaire presented three terms, "joint trouble", "rheumatoid arthritis", and "rheumatism", and some subjects apparently confused the three, in spite of the accompanying letter containing repeated detailed information.

As regards the use of the questionnaire as an instrument in diagnosing joint diseases or concentrating RA people to certain groups, information on symptoms referable to the hands, shoulders, and knees is of special interest. A *special study was made of these disease groups.* The diseases or syndromes concerned were for the *hands* 1) Heberden's nodes, 2) arthrosis of the CMC I or MCP I joints, 3) painful ganglia, 4) arthrosis of the PIP joints, 5) Dypuytren's contracture, and 6) painful conditions after major accidents. The diagnoses were clinical and made in typical cases.

The diseases or syndromes for the *shoulders*

Table 8. *Validity of information on joint symptoms in those denying joint symptoms on two occasions*
Percentages in italics

Age-group	I				II				III				IV				Total I–IV			
Sex	M		F		M		F		M		F		M		F		M		F	
Number	89		135		182		209		178		143		124		141		572		628	
Denying any joint symptoms	68	*76*	85	*63*	136	*75*	143	*68*	123	*69*	98	*69*	118	*95*	131	*93*	444	*78*	456	*73*
Results of examination: No joint disease	13	*15*	9	*7*	71	*39*	48	*23*	73	*41*	56	*39*	78	*63*	97	*69*	236	*41*	212	*34*
Results of examination: Diseases of hands	14	*21*	41	*48*	18	*13*	20	*14*	7	*4*	6	*6*	4	*5*	5	*4*	44	*7*	72	*11*
Results of examination: Diseases of shoulders	8	*12*	8	*9*	11	*8*	20	*14*	7	*6*	5	*5*	3	*3*	3	*2*	28	*5*	36	*6*
Results of examination: Diseases of knees	6	*9*	9	*11*	11	*8*	12	*8*	16	*15*	1	*1*	15	*13*	4	*3*	43	*8*	28	*4*

Table 9 *Results of investigation of those denying joint symptoms by questionnaire but not on subsequent telephone interview*

Percentages in italics

Age-group	I		II		III		IV		Total I–IV	
Sex ...	M	F	M	F	M	F	M	F	M	F
Number	89	155	182	209	178	143	124	141	573	628
Reporting joint symptoms in hands										
No. and % of total	4	16	5	11	10	10	3	3	24 *4.2*	40 *6.4*
No. of diagnoses for hands	1	17	5	8	4	2	1	0	12	28
Percentage of "correct" diagnoses by examiners	*25*	*94*	*100*	*73*	*40*	*20*	*33*	*0*	*50*	*70*
Reporting joint symptoms in shoulders										
No. and % of total	5	3	6	12	10	10	1	1	24 *4.2*	28 *4.6*
No. of diagnoses for shoulders	3	2	5	7	8	6	1	1	16	16
Percentage of "correct" diagnoses by examiners	*60*	*67*	*83*	*58*	*80*	*60*	*100*	*100*	*67*	*57*
Reporting joint symptoms in knees										
No. and % of total	4	15	11	17	13	10	1	4	28 *4.9*	48 *7.6*
No. of diagnoses for knees	3	15	8	11	4	2	1	0	16	32
Percentage of "correct" diagnoses by examiners	*75*	*100*	*73*	*65*	*31*	*20*	*100*	*0*	*57*	*67*

were 1) periarthritis (painful shoulder with limitation of movement), 2) cervical spondylosis with symptoms of pain radiating into the shoulders, and 3) habitual dislocation of the humero-scapular joint.

For the *knees* the conditions studied were 1) arthrosis, 2) joint effusion, 3) meniscus injury diagnosed at operation, and 4) state after severe damage with residual symptoms.

Table 8 shows the validity of information from those who denied joint symptoms on two occasions. Three-quarters considered themselves absolutely free from joint diseases, 76% of the oldest men, as against 95% of the youngest ones. On the other hand, the diagnosis of joint disease was not established in 15% of the oldest men, as against 63% of the youngest men. Of the oldest women 48% had joint diseases of the hands, as against only 4% of the youngest women. Somewhat lower figures were recorded for shoulders and knees.

The conclusion is that the information on joint symptoms from those who have denied such symptoms on two occasions is wrong in a large number of cases.

Those who primarily denied joint symptoms but reported symptoms referable to the hands, shoulders, or knees at a telephone interview constitute another group. Results of the investigation of this group are presented in Table 9 as num-

Table 10 *Number of diagnoses among those denying symptoms as percentages of examined*

Percentages in italics

Age-group, yrs.	Sex	Number of total diagnoses 0	1	2	3	4	Total	Mean number of diagnoses/person
70–74	M	*16*	*35*	*26*	*12*	*11*	89	1.69
	F	*8*	*24*	*29*	*23*	*16*	134	2.15
56–60	M	*44*	*29*	*16*	*10*	*1*	182	0.96
	F	*25*	*37*	*26*	*9*	*3*	208	1.30
42–46	M	*43*	*37*	*17*	*3*	—	178	0.80
	F	*44*	*36*	*15*	*4*	*1*	143	0.82
31 35	M	*65*	*25*	*8*	*2*	—	123	0.49
	F	*71*	*24*	*4*	*1*	—	141	0.35

Table 11 *Results of telephone interview with those who failed to appear for examination (denying symptoms on questionnaire)*

Percentages in italics

Sex	Age-groups I–IV M		F	
Reporting joint symptoms in hands	1	*0.7*	3	*1.8*
Reporting joint symptoms in shoulders	2	*1.5*	3	*1.8*
Reporting joint symptoms in knees	2	*1.5*	6	*3.7*
Denying joint symptoms	125	*93.9*	138	*84.1*
Total	133		164	

bers of diagnoses concerning hands, shoulders, and knees. *The true number of persons is lower* than the average number of diagnoses. Data on this problem are presented in Table 10. The highest average number of diagnoses, 2.15 per person, is found in the oldest women, and the lowest, 0.35 per person, in the youngest women.

Quantitatively the autodiagnoses of disease play a *relatively unimportant role, although they* may be fairly correct. In the men, for instance, only 21% of the total number of "hand" diagnoses occurred in those who reported diseases of the hands. The tendency is similar for diseases of the shoulders and knees.

Two of those 5 (3 men and 2 women) with *inflammatory joint symptoms had denied symptoms* at the telephone interview

Estimation of the number of joint diseases in those who were interviewed by telephone but did not appear for examination

The reporting of symptoms referable to the hands, shoulders, and knees is presented in *Table 11. The proportion of those reporting to* be in good joint health is significantly greater in *the group that failed to appear for examination* than in those examined (men $p > 0.001$ women $p > 0.05$).

Some important results relating to the function of the screening instrument

1 Persons with RA were *all* found in the *group that reported joint symptoms.*

2. Only a small proportion of the total number of RA persons were found in the groups reporting one or two symptoms

3 The RA persons who reported previous hospitalization for RA had a more advanced disease than had the other RA persons

4 *The proportion of the RA persons needing* care was equally distributed between those reporting and those not reporting previous hospitalization

5 The questionnaire method was unsatisfactory in separating persons with objectively and subjectively clearly diagnosable joint disease from persons without joint disease.

Choice of contrast groups

General considerations

As one main object of this investigation was to estimate the effect of RA on certain socio-medical parameters, the method of chosing contrasts to the RA persons had to be carefully considered. The influence of age and sex, e.g. on employment rate, is obvious.

The mode of selection of contrast groups has received comparatively little attention. Taube (1969), analyzing this problem, said that more often than not, the collecting of probands and contrasts is performed in such a way that a population at risk is not possible to define. Others, e.g. Cornfield & Haenszel (1960) and Eklund (1959), have also studied these effects. Several of the studies listed in Table 1 p. 13 on selection bias can be applied here.

As regards social factors in RA, Scotch & Geiger (1962) in a review on epidemiology concluded that there have been very few studies that meet even minimal criteria for scientific evidence and interference. They specially discussed the common absence of control groups.

An investigation on aetiological factors associated with RA was performed by the Empire Rheumatism Council in 1950. Contrasts, though matched for age and sex, were chosen among non-medical hospital staff, and among patients operated upon for hernia, fracture etc. The selection process of contrasts is not described. In the monograph by Short et al. (1957) on 293 RA patients and contrasts, the latter were admittedly matched for age and sex. 52 of them came from eye and ear outpatient departments and 201 were employed at the hospital. Persons with joint symptoms were excluded, but other details on the choice of contrasts were not reported.

The design of the New Haven study (Acheson, 1966) as well as of other studies, e.g. by Engel (1966), allows proper comparisons between diseased and healthy populations without appreciable selection bias.

In evaluating the effects of disease on employment, the absence of a properly selected contrast group is especially disadvantageous. Duthie et al. (1960, 1964), who followed 200 patients for 9 years, found that 71.5% had improved their social circumstances, but no comparison was made with a group of healthy persons. Manheimer & Benton (1960), reported that 47% of the men and 38% of the women in a severely handicapped group returned to work, but a contrast group was lacking.

The problem of comparison has sometimes been solved by comparing, e.g., the incomes in the disabled group with data from official statistics. This was done by Imell (1964), Imell & Kivlloog (1968) for asthmatics and by Mogensen (1967) for handicapped in Denmark.

Procedure for selecting contrasts

In order to avoid some of the drawbacks of previous investigations the following measures were taken:

(*a*) The contrasts were chosen from the same population as were the RA patients (see Fig. 4 p. 19).

(*b*) Contrasts were randomly sampled from those *denying all joint symptoms* in answering the questionnaire. Although no diagnosis was established in a not insignificant proportion of those *reporting symptoms* (see Table 7 p. 38) it would have been impossible to perform a meaningful sampling from this group.

(*c*) In view of the female preponderance in the RA group, 57 males/236 females, stratified sampling was performed. Twice as many females as males were sampled in advance for contrast groups.

(*d*) Persons with long-standing severe diseases and RA-resembling diseases in the contrast group were excluded (see Appendix tables 8 and 9 p. 128).

For the purpose of comparison with the RA group, the contrast group was therefore constructed so as to be derived from the same population, to be of the same age, to have about the same proportion between the sexes, and to be definitely healthier than the RA group, regarding both joint symptoms and other diseases.

Analysis of criteria and their implications

General considerations

The RA syndrome consists of different constellations of parameters, such as morning stiffness, joint pain, joint swelling, serologic abnormalities, and X ray changes. The purpose of an analysis of single parameters is to find a basis for evaluation of their levels of specificity sensitivity variability validity and subjectivity These levels are exemplified by data from the present study The degree of reproducibility and measurability varies widely between different items and between different factors within the same item. In some areas of epidemiological work feasibility will conflict with desired exactness. Lansbury (p. 274 in Hollander 1966) states that, "Perhaps a little information about *all* the joints is better than a lot of information about a few joints." Criteria to be used in surveys should be simple and inexpensive (Goslings & Cats, 1963). Finally Lawrence's statement that "... it is easy to criticize the criteria but difficult to improve on them" should be borne in mind (p. 113 in Bennett & Wood, 1968).

Morning stiffness

The common occurrence of morning stiffness in hospital cases was the reason for including this parameter in the 1956 criteria. Its presence and grading in population studies are purely subjective. Thelius (1969) reports that even in clinical research, objective measurement of joint stiffness has been restricted to finger joints. He found a discordance between subjective and objective joint stiffness. Thelius also reported strong correlation between increasing hand volume and decreasing objectively measured stiffness in the second MCP joints of RA patients. The minimum duration of 6 weeks proposed in 1956 was excluded from the 1961 criteria. In the RA criteria of 1966 morning stiffness was excluded altogether However it was *retained* in the criteria for active polyarthritis with the stipulation that the stiffness recorded should be localized to the limbs and to be of a duration of at least 15 minutes but must not be present all day

Morning stiffness is a common complaint. In Engel's et al. study (1966) 22.1% of men and 32.3% of females reported such stiffness, in most cases being of short duration. Feldman et al. (1958) found morning stiffness in 8% of their subjects. Rubin et al. (1956) reported 29% positive answers to a question on morning stiffness among those *not* having RA. In the Tecumseh study by Mikkelsen et al. (1963) 15.7% of males and 19.5% of females reported morning stiffness. The occurrence of morning stiffness thus varies considerably from survey to survey

Present investigation

For age-groups 42–46 and 31–35 years, morning stiffness of more than 1 hour's duration was recorded. Among those reporting joint symptoms, morning stiffness was found in 20% of the age-group 42–46 and in 10% of the age-group 31–35 years, which contrasts to the RA prevalence of 4.6% and 1.7% respectively Thus, applying morning stiffness as a criterion for RA even to a group *with* joint symptoms renders it a low specificity Also the validity of answers is low Of 254 persons in the age-group 42–46 who on the questionnaire reported rheumatism, joint swelling, and morning stiffness for more than 1 hour only 74% were on examination recorded as having morning stiffness of this long duration. The corresponding proportion for the age-group 31–35 was only 41% Though not systemically recorded, it was experienced that many of the respondents answered the question on morning stiffness in a fairly vague manner implying a poor definition of the word. A time-limit as low as 15 minutes, as stipulated in the 1966 criteria for active polyarthritis, will produce figures with low substance. Partly for this reason a high time limit of 1 hour were here required for qualification.

Special considerations

The number of people reporting morning stiffness increases with age (Engel, 1966). In the psychological literature many experiments have been made to assess the difference between subjective and objective time. McGrath & O'Hanlon (1967) found great variation between individuals in this respect but for a certain individual the ratio between subjective and objective time was constant and independent of time elapsed. Unpleasant experiences were found to lead to an overestimation of real time (Ekman et al. 1966), readily applicable to morning stiffness.

Collen et al. (1969) found a great instability in answers to a question on morning stiffness of 30 minutes duration or more. Of those initially answering positively 40 % of men and 25 % of females changed their replies, when requestioned, from "Yes" to "No" and very few the reverse. Laine (1965) classed morning stiffness as a minor criterion for RA. O'Brien et al. (1968) found that morning stiffness indicates the presence of osteoarthrosis (OA) with a fair degree of sensitivity. Hall (1966), studying an African hospital population, reported that a history of morning stiffness was almost impossible for a stranger to evaluate. In Collaborative review of diagnostic criteria (Prague, 1969) a considerable difference was found between different rheumatological centres in eliciting morning stiffness by Cobb's question and by the physician's assessment. For the 272 patients from the USSR, the physicians' assessments yielded 20.3 % less patients with morning stiffness than did Cobb's question. For the other four participating countries the result was the reverse. Virtually all figures on the prevalence of RA reported up to now include morning stiffness.
yielded 20.3 % less patients with morning stiffness than did Cobb's question. For the other four participating countries the result was the reverse. Virtually all figures on the prevalence of RA reported up to now include morning stiffness.

Conclusions

Morning stiffness as a variable commonly used in population studies of RA is poorly defined both by laymen and by rheumatologists. Objective measurements have only been applied to small joints. Cobb's question on morning stiffness also concerns a painful experience which contributes to the vagueness of its definition. Specificity, sensitivity and stability of answers are low. Different languages probably define morning stiffness in very different ways. Its value in detecting RA and polyarthritis is therefore strictly limited.

Joint pain

General remarks

Hart (1968) presented a general concept of pain experiences in rheumatic diseases. He stressed the complex and individual nature of pain and its central position in disease. "Only the patient knows what he experiences.

Laine & Lemmen (1960) pointed out that in many cases pain is more important than anatomical changes because of its strong phenomenal influence on the total behaviour Sherman (1943) and Wilder (1940) found that females were more sensitive to a standardized pain than were men. He also noticed that Indians were relatively unsensitive to pain. Zborowski (1952) pointed out cultural differences with respect to pain.

As emphasized by Beecher (1957), however in a comprehensive survey of pain literature, pain remains uncommonly difficult to define Hardy et al. (1967) stressed the difference between pain sensations *per se* and pain reactions. Salicylates influence mainly the pain threshold but opiates and alcohol affect the pattern of reaction to pain.

Questions on joint pain

Kast (1968) considers that a good pain evaluation should be based on the relationship between the patient's verbal assessment of his pain and his behavioural evidence of suffering" Questions should at least elicit the presence of joint pain. In collaboration with Rosenbaum, Cobb (1956), in one of his guiding works on an interview measure of RA, found that doctors recorded some 20% more joint pain than did interviewers and that this difference was more pronounced for female respondents. However a 25% reduction of positive answers on re-questioning on joint pain by questionnaire establishes the presence of joint pain as strongly dependent on the method, interviewer and environment (Collen et al., 1969). This has been focused by Mason et al. (1967) In a therapeutic trial they recorded that a female doctor suffering from RA, gave the same RA patients significantly higher scores for pain than did the other doctors. Questions given *after* an examination of joints result in a considerable increase of positive answers (Acheson et al., 1969).

Measurement of RA joint pain

The measurement of joint pain in RA patients is central and difficult. There are principally different ways to attack this problem. The application of a standardized pressure on a joint thus provoking tenderness was introduced by Steinbrocker (1949). His idea was developed by e.g. McCarty et al. (1965 1968), who could demonstrate good reproducibility of tenderness measurements on finger joints. As joint pain includes both pain *and* tenderness, Lansbury (1964) has suggested that the amount of spontaneously consumed aspirin is a sufficiently good measure on the severity of pain. He demonstrated a correlation between this consumption and general disease activity Bedford (1951) studied diurnal variation of subjective pain in RA and found it to be considerable. Lansbury (1964) also presented a system of weighting pain experience by which a painful hip and knee scored higher than wrist and toes. In my opinion, this weighting is up to the patient and not to the doctor Ingpen (1968) measured patients' subjective pain assessments indirectly using the grip-strength test and found a good positive correlation. The complex nature of grip strength and what it really measures are discussed by Ingpen (1968) and Ritchie et al. (1968), but the latter authors did not measure functional capacity They reported a strong correlation between their index on joint tenderness and the articular index recommended by ARA ($r = 0.89$).

Beecher (1965) stated that placebo is 10 times more effective in relieving pain of pathological origin than it is in relieving pain of experimentally contrived origin The great influence of placebo on pain within rheumatology has been shown by e.g., Clark (1951) Traut & Passarelli (1957), and Morison et al. (1961).

Table 12. *"Pain" definitions in RA group* (%)

No. of persons	Preferred word for long-standing hurtful feelings in joints			"Tenderness" is hurtful feeling		"Pain" is hurtful feeling		"Ache" is hurtful feeling		"It is possible to suffer from tenderness and pain at the same time (correct)
	"Pain	"Tenderness"	Ache"	On pressure (correct)	Without pressure (false)	On pressure (correct)	Without pressure (correct)	On pressure (false)	Without pressure (correct)	
284	*17*	*16*	*67*	*90*	*63*	*82*	*86*	*20*	*97*	*79*

"Pain" problems and definitions in this survey

Time

A *history* of joint pain, as mentioned in New York criterion no. 1 covers a much broader concept, including at least pain on rest. The inclusion of both these aspects in *one* criterion is not necessary It could easily be split up into two, one for a positive history and one for the findings by examination. In this investigation the 1966 criterion no. 1 for RA includes only cases with pain on motion and/or tenderness found at examination. Age has also a considerable influence on the amount of pain experienced in RA (see p. 83). It should also be pointed out that pain on motion is dependent both on the force applied and the range of motion.

Localisation

After examination of some 2 000 persons with joint symptoms during the screening procedure, I considered that it was impossible to record a graded joint pain or tenderness and that it would give a false impression of accuracy On the re-examination of the RA group, pain and/or tenderness were recorded in each joint but only as present or absent.

Pain on motion and tenderness were recorded separately In these recordings were used conventional definitions and not the patient's definitions of pain

For several persons it turned out to be difficult to define whether a certain pain was located to a joint. This experience is recognized by e.g Vainio, p. 153 in Hijmans et al. (1969), and Lawrence et al. (1966 *b*). Guidance through careful questioning was not always successful in helping a person to locate pain. It is necessary to examine a person with multiple joint pain slowly so as to avoid irrelevant answers to questions on pain. Several RA persons also present painful extra-articular lesions.

Tenderness

The pain concept of the ARA, Rome, and New York criteria includes pain on motion and tenderness. A splitting-up of "pain into pain on motion" and tenderness" was discussed by Burch & O'Brien (1965) on the basis of data from their study of the Blackfeet Indians. By means of chi-square analysis they concluded that the high association between "pain on motion" and "tenderness did not justify such a splitting-up of the pain criterion. Laine (1965) considered that pain on motion or tenderness" was a too unspecified criterion.

The results of the investigation by Ritchie et al. (1968) on RA were unknown to the writer when this study was planned. They used an index of joint tenderness, applying a grading from 0 to 3. There was a high inter-observer agreement on this index (correlation coefficient 0.91–0.98).

It is obvious that the provoking of tenderness is a matter of the force applied. It is probable and has been shown by Ritchie et al. (1968) that the pressure applied by *one* examiner does not vary considerably but might differ greatly from that applied by *another* examiner The subjectivity of both the observer and the examinee with respect to tenderness was believed to be inevitable in practice.

Semantic definitions of pain tenderness, and ache

During the investigation it became clear that the definitions of pain experiences used by diseased persons differed from the conventional definitions given in dictionaries. When doctors use the same terms as an average patient, these terms are probably more accurately defined by the doctor Therefore the magnitude of these distorted def

initions of pain terms was investigated. An interview form was used (Appendix IV p. 132). Nine persons were excluded because of marked inability to understand the difference between the questions. Results are presented in Table 12. As there were no significant differences as to age, the numbers refer to the whole RA group.

The most significant finding was that 63% falsely defined "tenderness" as a "hurtful feeling present without pressure". However 90% used "tenderness" according to the correct definition. 21% believed falsely that "pain" and "tenderness" exclude each other.

The conclusion is that "ache" is best, "pain" well, and "tenderness" least understood. As "tenderness" is a sign of acute inflammation, the communication between doctor and patient might thus be impaired.

General conclusions on "pain"

The "pain" concept is an extremely complex variable within rheumatology and includes varying forms of distress and inconvenience. As it is highly dependent on verbal communication, the "pain" conception inevitably implies instability in time and grade. For estimating differences in, and general impact of pain it is therefore especially essential to have detailed information of data-collecting procedures.

Joint swelling

General comments

n the Leigh and Wensleydale surveys 48 % (78 ases) of all the RA cases were diagnosed on a linical basis only (Kellgren 1966). Engel et al. 1966) found that 10.59 % of women 65–74 years ld had symmetrical joint swelling. The recogni-on of joint swelling has a great influence on total revalence of RA.

In all *four* sets of criteria used from 1956 to 966, joint swelling (one joint, two joints, sym-metrical) has been given great weight. It must be emembered that the criteria were originally de-gned from hospital-patient data for use in hospi-al patients and mostly not out of survey experi-nce. Joint swelling, as specified in the Rome riteria of 1961 includes either soft-tissue hickening or fluid. Objective methods to estab-sh whether joint swelling is present or absent do ot seem to have been published. On the other and, methods to measure *changes* in swelling of he hand or foot and of separate joints have been resented (Lansbury 1964) (Smyth et al., 1963).

In a population survey a statement on joint welling will be founded on an estimation of the lasticity felt on palpation of the joints, together vith findings on inspection.

In comparison with the great number of studies levoted to serological and radiological findings, nly a limited number of reports concern prob-ems of evaluating joint swelling. Lansbury (1964) liscards measurement of joint swelling in the valuation of therapeutic effects, because it is dif icult to grade and might imply acute inflamma-ion as well as *permanent structural changes.* The reat difficulties in evaluating joint swelling were tressed by Laine (1962, 1965). Others, e.g. Lincoln & Cobb (1963), are more optimistic and tate that RA causes easily recorded symp-oms and readily observed signs Most sur eys do not report any difficulties in the recording nd grading of joint swelling. O'Sullivan et al. 1968), however studying joint manifestations in 381 persons, found an agreement on a presence of joint swelling as low as 16.9 % between two ex perienced examiners.

All joints have not equal chances of being diagnosed as swollen. *It is probably much easier* to diagnose clinical swelling of PIP or MCP joints of the hands than of hip joints, ankles, shoulders, and toes. This implies *less* chance for joints ex cluded in the New York criterion no. 2 to be diagnosed as being swollen. Comments along *these lines* were attached *to the 1966 criteria.* Lawrence et al. (1966 *c*) found that in 27 out of 48 probable RA cases the diagnoses were founded on minimal bilateral swelling in the knees. It has therefore been questioned whether such swelling should qualify for a RA diagnosis.

Obesity does not seldom *influence* the estima-tion of joint swelling. This is especially relevant to the ankle and knee but is also valid for the wrist. The situation is complicated because of a positive correlation between obesity and the oc currence of painful joints (Lawrence et al 1966 *b*). Under certain conditions, soft tissue swelling can also be evaluated from X-ray films.

Results from the present survey

To obtain an estimate of the magnitude of the doubtful-swelling problem, data were collected *from those reporting symptoms in age-groups 56–*

Table 13 *Grading of joint swelling. Symptom-reporting groups.* (*For the 56–60 and 42–46 age-groups 52 % and 38 %, respectively of the total number of respon-dents*)

Figures (%) refer to screening examination.
Percentages in italics

Age-group, yrs.	Sex	Nos. of examined	Joint swelling: Absent	Doubt-ful	Definite: Non RA	Definite: RA
56–60	M	587	*77.7*	*12.9*	*3.6*	*5.8*
	F	974	*54.3*	*26.2*	*7.7*	*11.8*
42–46	M	633	*86.3*	*8.5*	*2.5*	*2.7*
	F	966	*77.9*	*12.0*	*4.2*	*5.9*

60 and 42–46 years. In Table 13 doubtful and definite swellings are recorded without reference to site. There are more cases with doubtful swelling among females than among males, maximum being 26.8% for females in age-group 56–60. More than 50% of diagnosed joint swelling is found in the RA-group.

The need of an unbiased observer

The degree of influence of specialized pre-knowledge on disease patterns, and thus, on the prevalence of a disease is seldom discussed. Rose, in discussing Valkenburg's (1968) report, stated that

I realize that is what Rome did to us—it brainwashed me so that I stopped producing Pittsburgh figures for RA and found Manchester figures instead.

The epidemiologist has a general idea of the symptoms and diseases he is looking for and this idea probably emerges mainly from clinical experience. He cannot break loose from clinical thinking and should therefore tend to take an extra look for e.g., symmetry and swelling. Under these circumstances the knowledge of diseases distorts the "true" observations in the direction towards a picture known from clinical cases.

Conclusions

The importance of the diagnostic finding of joint swelling has been comparatively little studied in population surveys. A poor interobserver reproducibility has been reported. In the present survey doubtful joint swelling was especially common in females 56–60 years old.

Limitation of joint movement

General considerations

┐ the New York criteria were introduced, of movement was not considered separ y The complex nature of restriction of joint ty has been discussed by Williams & Hostert 1957) and Williams (1952). They noted six dif causes of restriction of joint movement, them pain, swelling, and muscle spasm. .indahl (1968) considered that the reproducibility measurement of joint mobility was fairly low .benker (1966) has devised a method to measure mobility in MCP and PIP joints but does not his opinion with figures.

Data on the distribution of this parameter in opulations have not been published. The testing recording of range of motion in all joints, as ibed, e.g., by Marton (1959), is virtually im- ble in population surveys and of restricted alue. However in collaboration with Thorsteins- on, the writer using a special device, studied the ange of movement for MCP I, wrist, shoulder nd hip in an Icelandic and a Swedish population. have not yet been published but show a light decrease in range of movement with in- .sing age. The inter-observer error was low or the shoulder joint.

It is therefore probable that limitation of movement is the object for less subjectivity than is joint swelling. However the discussion on the unbiased observer in the chapter on joint swelling (p. 47) is also valid in this context.

Present survey

In the present survey limitation of movement was a subjective measure. In clinical materials of RA, e.g. that published by Ennevaara (1967), limitation referable to the shoulders is frequent, but it is also common in the population as a whole. In the present survey 23.6% of those in age-group 56–60 suffered from *painful* limitation of shoulder-joint movement. One-fourth of them were found among those *denying* all joint symptoms. The condition was more common among males than among females, comprising 27.2% and 22.7% respectively According to Berkson s fallacy (Berkson, 1946 Andersen, 1969 *a*), painful shoulders with limitation would be over represented in a clinical material of RA.

In conclusion, limitation of movement is a common finding, has various origins, and is slowly increasing with age, but is proabably less a subject to observer errors than is, e.g., joint swelling.

Radiological findings

General considerations

It is generally agreed that radiological data involve the least observer error among the parameters contributing to the RA syndrome. As the X-ray film is also a permanent record, great weight has been attributed to the radiological findings in diagnosing RA. However it cannot be considered generally appropriate to render one easily recognisable and recordable finding *more* weight in the diagnostic process. If this is done, as by Nørgaard (1969), the arbitrary way of constructing syndromes and syndrome clusters (Wulff 1969) should be borne in mind.

Distribution in population

In clinical materials (e.g. Sievers, 1965), the main radiological finding, erosions, is common and highly correlated with a positive SSCT In population studies, however erosions without clinical symptoms are quite common. Cathcart et al. (1968) reported that only 4 individuals out of 9 with solitary erosions had clinical evidence of RA. Kellgren & Lawrence (1956) found that 25% of males and 18% of females 55–64 years old had hand erosions of grade 1 or higher Only 50% were graded 0 for RA, if all available films were considered. As many as 26 persons with only radiographic signs of RA were found, as against 45 in whom both X-ray and serology were positive. Engel et al. (1966), however found positive X-ray in only 0.3% of the non-RA population, as against 11.3% of the RA population. This implies, however that the majority of persons with X-ray changes fall outside the RA population. In figures from the combined Leigh and Wensleydale surveys (Kellgren, 1966), 13% of the total number of RA cases were diagnosed on X ray findings alone. Cathcart et al. (1968) reported that out of 820 individuals only 2 fulfilled the strict radiological criteria established at the Rome symposium in 1961

Classifications

General remarks

In population studies X-ray films should be read without the reader knowing any clinical data. The influence of the reader's knowledge of diagnosis on X ray classifications has been stressed by Bland et al. (1969). They reported that the reader's knowledge of clinical diagnosis increased the number classified as having radiological RA. Short et al. (1957), on the other hand, emphasized that roentgenograms must be interpreted in the light of clinical picture This illustrates the difference between clinical and epidemiological work.

A grading for RA from 0 to 4 was suggested by Kellgren (1956), who reported a correlation coefficient of +0.80 between two readings with respect to this grading. As was expected, the unanimity of grading was lowered with falling grade of RA but, on the other hand, absence or presence of RA was determined "with some certainty" (Kellgren & Lawrence, 1957 *a*).

In the criteria of 1961 and 1966, a minimum grading of 2 was considered to fulfill the radiological criterion of RA. Lawrence and Kellgren have applied this grading in their later work, and it has been generally accepted. Radiographs of *total* hands or feet illustrating different grades of radiological RA have been presented (Kellgren et al., The Epidemiology of Chronic Rheumatism, 1963 Vol. II). Radiographs of separate joints illustrate the grading used in the National Health Examination Survey (Engel et al., 1966) and such X ray films are also presented by Lawrence (1965). Recordings of separate joints are obviously important because of the joint pattern of RA. Cathcart et al. (1968) presented a weighted classification of X-ray findings giving erosions higher weight than other signs, such as juxta-articular osteoporosis and subluxations, but did not consider the site of findings.

Erosions

central finding in the diagnosis of RA is the sion. Osteoporosis was excluded from the 1966 Lawrence (1965) mentioned that a defi- to grading of erosion was not made, unless it seen in profile and a definitive break in the was noted. Other problems in this field are quality and projection. At the ordinary pro- a true erosion might be missed, because break-through of the cortex will not be re- Further bone cysts might be confused th erosions. In contrast to the cyst, an erosion d be surrounded by an area of decalcifica- (de Graaff et al., 1963). Another problem is e distinction between RA and OA which, at gher ages, will be difficult or impossible (Miall al., 1958). Even in the 1956 criteria it was that the presence of OA did not exclude diagnosis of RA. The localization of erosions also be important. Erosions in the joint argins are generally classified as RA, but when involve the joint surface their origin is (Laine, personal communication, 1968). Some authors (e.g. Sievers, 1965) use the of erosions as a measure of severity of A. This is no problem as far as small defined erosions are concerned. In the case of bigger erosions the diagnostic work leaves the present-or absent area and transfers to grading of severity

Results from the present survey

Cysts were recorded for each joint. Their presence and number increased with age. Cysts in the MCP joints were present in 19% of the age-group 70–74 and in 6% of the age-group 56–60. More than three cysts in one person were found only in the highest age-group.

Conclusions

X-ray films of hands and feet, although not free from subjective influence, can be graded for and within RA with acceptable accuracy The classification generally used is partly not formalized, because it does not specify site of lesion. A considerable number of persons have radiological changes classified as RA without clinical symptoms. However the fact that X ray findings are the most stable and reproducible of the RA criteria does not automatically imply that X-ray changes are the most "true of the RA criteria.

Radiological findings

General considerations

It is generally agreed that radiological data involve *the least observer error among the parameters* contributing to the RA syndrome. As the X ray film is also a permanent record, great weight has been attributed to the radiological findings in diagnosing RA. However it cannot be considered generally appropriate to render one *easily recognisable* and *recordable finding more* weight in the diagnostic process. If this is done, as by Nørgaard (1969), the arbitrary way of constructing syndromes and syndrome clusters (Wulff 1969) should be borne in mind.

Distribution in population

In clinical materials (e.g. Sievers, 1965), the main radiological finding, erosions, is common and highly correlated with a positive SSCT In population studies, however erosions without clinical symptoms are quite common. Cathcart et al. (1968) reported that only 4 individuals out of 9 with solitary erosions had clinical evidence of RA. Kellgren & Lawrence (1956) found that 25% of males and 18% of females 55–64 years old had hand erosions of grade 1 or higher Only 50% were graded 0 for RA, if all available films were considered. As many as 26 persons with only radiographic signs of RA were found, as against 45 in whom both X ray and serology were positive. Engel et al. (1966) however found positive X ray in only 0.3% of the non-RA population, as against 11.3% of the RA population. This implies, however that the majority of persons with X-ray changes fall outside the RA population. In figures from the combined Leigh and Wensleydale surveys (Kellgren, 1966), 13% of the total number of RA cases were diagnosed on X ray findings alone. Cathcart et al. (1968) reported that out of 820 individuals only 2 fulfilled the strict radiological criteria established at the Rome symposium in 1961

Classifications

General remarks

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...tre (Lawrence, 1967). Average rate of positive was 3.4% in the survey in the US by Engel al. (1966). They found 19 6% BFT positives in rheumatoid population, as against 2.6% in the -rheumatoid population. The percentage of FT positives, especially with high titres, de y with increasing education.

There are obviously geographical differences in distribution of positive rheumatoid factor a. Lawrence et al. (1966), in comparing data eight population surveys in Europe and ca, found that SCAT positivity varied be 1.0% in Watford and 9.2% in Arizona. No bvious relationship either with latitude or ethnic was discovered. Boyle & Buchanan (1968), to the Wensleydale survey found a tive SCAT in only 19% of those with clinical /or radiological evidence of inflammatory yarthritis.

Females generally show more positive serologi- l reactions than do males (Bennett & Burch, 968). For females with OA in five joints or Valkenburg et al. (1966) found that 22% a positive LFT

Valkenburg (1963) and Valkenburg et al. (1968) compared serological findings from populations of temperate and non-temperate areas and ound great discrepances with respect to the per centages of positives as well as to the inter relationships between Waaler-Rose and LFT reac ions. Their conclusion was that the SCAT and LFT reactions operate independently They also found that the influence of severe tropical diseases on the rate of positive reactors was insignificant.

Follow-up studies of serological tests have been made by e.g., Ball & Lawrence (1963) in Great Britain and Mikkelsen & Dodge (1969) in the US. In the latter survey only 49 out of 105 persons with a positive LFT as the single finding were still positive at the five year follow-up. Ball & Lawrence reported a high incidence of RA among those initially serologically positive. However all combinations of changes within serological tests were observed. Adler et al. (1967 *b*) in their Jerusalem study found that 65% of LFT positives were negatives on a follow-up 6–9 months later In clinical materials, observations have been made by Graudal (1968) who found that about 1/5 of the patients fluctuated between positive and negative reactions. *Jarløv* (1968) reported on a follow-up of 30 seronegative RA patients. He found that 5 patients suffered from LED 5 patients had no signs of rheumatoid or other collagen disease, and 7 had RA but had become seropositive.

Conclusions

The close interrelationship between positive serological tests for rheumatoid factors and the hospi tal diagnosis of RA, weakens markedly or even dissolves, in population studies. In several populations most persons with positive reactions do not, in fact, suffer from RA. The serological reac tions are better looked upon as a separate entity even if for some populations, the interrelationship between separate tests is weak or absent.

Special criteria problems

Weighting of criteria

In the hitherto widely used sets of criteria from 1956 1958, 1961 and 1966 weighting that gives one or two criteria more weight in a summation has not been officially" recommended. "The ARA criteria of 1958 embrace two gradients, one of the probability of the diagnosis and the other of the severity of diseases. Both gradients are valuable, but are better not confused. The ideal severity gradient would be a functional grading" (p. 176 in Population Studies of the Rheumatic Diseases, 1968. Report from the subcommittee on diagnostic criteria for rheumatoid arthritis). It is, however fairly clear that in general the probability of disease should be positively correlated to at least some measures of severity This is discussed in detail on p. 82. The method that gives morning stiffness as much diagnostic weight as a high titre of SSCT would seem inadequate from the view point of both specificity and sensitivity

The tendency to give an easily measurable sign more weigth than a subjective symptom in diagnostic thinking makes us stick to the conventional diagnostic process characteristic of hospital work. The widening of the knowledge of the diagnostic process, which a population survey implies and which leads us away from diseases to syndromes, would then be partly lost.

Weighting of criteria generally based on a hospital diagnostic process, has been discussed by several authors. Coste (p. 176 in Bennett & Wood, 1968) gave positive serology X-ray changes typical of RA, and subcutaneous nodules extra weight ("major criteria").

Before Coste critized the *1961* criteria, Laine (1965) drew attention to the same problem, and also emphasized the effect of time and treatment, especially with corticosteroids, on the criteria.

Major *(erosions)* and *minor (osteoporosis)* radiological criteria have been proposed, e.g. by Cathcart et al. (1968).

Lawrence (1963 *b*), on the other hand, pointed out that *rheumatoid* arthritis would appear to be the exception in persons with a positive SCAT"

Exemplified by data from the Jerusalem survey of *RA*, Abramson (1967) published a close analysis of the reliability validity and scalability of the ARA criteria. He found that the six clinical criteria could be arranged as a set which met the *criteria for appraisal of a Guttman scale.* Abramson supported the view that the scalability of these criteria indicated that they measured a single dimension.

The central *problem of a diagnosis in general* is not even partly solved by weighting of criteria but weighting might be applied to hospital series and in therapeutic trials.

Exclusions

General remarks

In the first 1956 criteria *for RA* (Ropes et al., 1956) it was stated that although they might fulfill certain criteria for RA, typical clinical cases of 19 specified non-RA diseases should be excluded. *In the 1958 revision of these criteria* exclusions were virtually unchanged. The Rome criteria of 1961 include 21 diagnostic exclusions.

These exclusions, however are seldom presented in survey reports. Kellgren (1968 *b*), in three surveys, found only 15 exclusions and 147 RA persons, implying an *insignificant influence* on RA prevalence figures.

As criteria represent a road to better under standing and definition of disease, the exclusions are mainly unstructurized clinical diagnoses and are based on investigations impracticable or impossible to use in survey work. Criticism along these lines by Acheson (1965), Cobb (1963), and Kellgren (1968 *b*) resulted in a statement accompanying the New York criteria. "Exclusions are generally undesirable and impracticable in population studies.

Present study

In the present survey only a limited number of exclusions were considered. The diagnoses were

Table 14 Changes in numbers of criteria for polyarthritis (Rome 1961 New York 1966) from 1st to 2nd examination of initial RA group of 326 persons

Weighted numbers

		Re-examination Number of criteria for polyarthritis (New York, 1966) (% of examined in each group of criteria indicated by italics)						Total no. of examined	Not re-examined (numbers and % of available)	Total
		0	1		3	4	5			
1st examination										
Number of clinical criteria for RA (Rome, 1961)	3	2	5	21	34	12	15	89	1	90
		2	*6*	*4*	*38*	*13*	*17*		*1*	
	4	5	3	20	9	37	17	91	3	94
		5	*3*	*22*	*10*	*41*	*19*		*3*	
	5	0	5	4	5	28	62	104	10	114
		0	*5*	*4*	*5*	*27*	*60*		*9*	
	6	0	1	0	1	2	16	20	4	4
		0	*5*	*0*	*5*	*10*	*80*		*16*	
Clinical criteria for inactive RA (Rome, 1961)		0	1	1	1	0	1	4	0	4
		0	*25*	*25*	*25*	*0*	*25*		*0*	
Total no. of examined		7	15	46	50	79	111	308	18	326
		2	*5*	*15*	*16*	*25*	*36*		*6*	

based on clinical picture and history mostly supplemented by information from hospital records.

In the symptom-reporting groups a total of 30 males and 16 females (weighted numbers) were excluded. Among the males ankylosing spondylitis and Reiter's syndrome dominated, each represented by 9 cases. A total of 7 cases of gout were found—a low prevalence—which to a large extent was the result of the diagnostic method used.

In the symptom-reporting groups, 180 persons (1.1% of the population) reported a history of rheumatic fever with polyarthritis but without clinical residuals. This figure is definitely lower than those 5% of males and 7% of females reporting a history of polyarthritis in the Leigh survey. This probably reflects an earlier lower prevalence of rheumatic fever which nowadays is virtually eradicated in Sweden. Out of 1 201 examined in the groups denying joint symptoms, only 7 "exclusions" were recorded and 4 of them had postinfectious arthritis.

Conclusions

From a theoretical viewpoint, exclusions as used in RA surveys represent an area of low substance. However it is felt that practical reasons and common sense would well justify the use of exclusions, especially as they are quantitatively of minor importance.

Diagnostic inconsistency

General considerations

From the foregoing presentation of the elements building up the RA syndrome it is obvious that a diagnosis always involves a time factor. All criteria, besides observer variation, show changes with time. This has implications as to prognosis. Groups of early RA cases will, *per se* include more non-RA cases than will groups of later stages of RA. The shorter the history of any sign or symptom, the greater the diagnostic uncertainty. As an example, a point prevalence study on water might find the same amount of water in the small lake as in the fast-flowing river.

Follow-ups of prevalence studies are not often made. The better prognosis for early cases, as concluded by e.g., *Duthie et al. (1955 1964)* and Duthie (1967) is most likely less a measure of prognosis than of diagnostic inconsistency. Berkowitz et al. (1968) performed a follow-up of patients who had been labelled "arthritis" Out of 68 availables, 11 had no symptoms or signs of arthritis. In only 33 was the follow-up diagnosis the same as the initial one. At follow-up of 55 patients originally labelled as possible or probable rheumatoid arthritis 6 had classical rheumatoid arthritis and 12 had no musculoskeletal disorders. Results in the same direction were reported by Mikkelsen & Dodge (1969) and Laine (1965).

Beall & Cobb (1961) and Lincoln & Cobb (1963) systematically evaluated the influence of time on a mixed prevalence-incidence measure of RA. They found that according to their definitions, 47% of 331 industrial workers on at least one occasion during an examination period of 29 months fulfilled the criteria for possible disease.

Data from the present survey

The re-examination of the primarily screened group after 18–33 months offered a possibility to estimate the influence of diagnostic inconsistency. Results will be found in Table 14. With increasing numbers of clinical criteria fulfilled at the first examination the numbers were more stable. Of those with three clinical criteria at the first examination, 38% remained in this group as against 60% of those with five criteria.

During the observation period of 8 to 27 months among those initially denying joint symptoms, 11% entered the group of one or more clinical RA criteria.

Conclusions

Time causes considerable inconsistency in the point prevalence diagnosis of RA, especially in the cases that fulfill few criteria. This applies not only to population surveys but also to clinical materials and affects, among other things, our view of the prognosis.

What is rheumatoid arthritis? Concluding remarks on the analysis of the criteria

In a recent textbook Kellgren (1968 a) points out the *diagnostic dilemmas partly induced and* focused by the results of epidemiological work on RA. This work has not, hitherto, produced data of crucial importance to the pathogenesis of RA.

On the other hand, population surveys imply a broadening concept of RA disease but nevertheless the results have meant something of a challenging confusion at a higher level. The separate elements which build up a syndrome or a disease are to some extent "purely" medical, such as serological and radiological findings. However the important influence of sex, age, education, semantics, and race on prevalence adds to established psychological facts relating to observer variance, perception, and impact of situation on the collection and interpretation of information. A diagnostic emphasis on important pathogenic data from serology and radiology might primarily lead one away from patients into a mass of difficult-to-interpret positive laboratory findings in symptom-free individuals. It must also be stressed that the RA syndrome includes not only joint manifestations but also changes of general nature.

Therefore, a point prevalence estimate of RA, or a syndrome in general, is a practical compromise in order to extract at least some data, some variations of which are known, out of a complex dynamic situation in a population.

Strict *epidemiological* diagnosis deals with *groups of persons*. *Clinical* diagnosis concerns *patients*. The primary aim of a diagnosis is to form a sound basis for individual medical treatment. It is obvious that in *this* respect a clinical therapeutically orientated diagnosis made at a well-equipped clinic not seldom is firmer than and qualitatively superior to the epidemiological diagnosis. In *clinical diagnostic work*, the mind of the experienced doctor in fact handles astronomical amounts of data from different sources where usually not firmly structurized knowledge, experience, and intuition influence each other fairly informally. The *epidemiologist*, on the other hand, forms *his* image of a diagnosis using strong efforts in achieving representativity, conformity of recording and handling of multipersonal data in close contact with individuals, but at the expense of deep-going individualized information. This does not result in any calm self-assurance but instead implies an exiting confrontation with an essential question, "what is disease?"

From a clinical viewpoint, the epidemiologist's preference of representativity to individual clinical exactness, is finally a matter of a slightly to moderately different structurizing of essentials in the clinical picture of a disease. As hospital materials, in the field of chronic diseases, do not cover the full picture of a disease, questions limited to "right or wrong" in diagnosis will mostly lead to a dead end. The fact that epidemiologist and clinician can be one and the same person might reduce the sometimes negative effect of this *per se* moderate form of diagnostic schizofrenia.

CHAPTER XVI

Basic data on RA and contrast groups

This chapter will be an introduction to the RA material used in the analysis. The RA group was defined as those fulfilling more than one New York criterion for RA and will be found in the right part of Table 15 Weighted numbers are used.

RA group

Prevalence spectrum of RA

It will be seen in Table 15 p. 58, that the crude prevalence for RA in the population examined is 2.7% The prevalence spectrum, however should consider age, sex, and number of criteria.

The highest prevalence, 7.2% was found for females 56–60 years fulfilling ≥3 Rome criteria. The lowest prevalence was found for females 31–35 years, fulfilling four New York criteria, in this group of 2 159 no such RA persons were identified. For the New York criteria the span between strictest and widest definitions was 4.7-fold for total males and 6.4-fold for total females, implying a greater span for females. The span between the group with only clinical New York criteria, and that with clinical plus positive serology or radiology was for males 2.1 and for females 2.6.

Age differences are pronounced. The highest prevalence is noted in age-group 56–60 years but there is no statistical difference in prevalence between this group and age-group 70–74. There are, however, highly significant differences in prevalence figures between age-groups 56–60 and 42–46 for both sexes ($p < 0.001$). The highest prevalence among those fulfilling ≥3 clinical criteria (Rome) plus positive X ray and serology 1 6% is recorded for females in age-group 70–74 and is falling with age.

Because of sampling errors (see p. 26) many comparisons made between prevalence of RA in different surveys may not be valid.

In conclusion, the prevalence spectrum of the present survey does not differ in any essential way from those of other European investigations reviewed by e.g. Wolfe (1968), Adler et al. (1967 a), and de Graaff et al. (1963). In the present survey with exceptions for the RA group, serological and radiological data were not collected in the symptom-reporting groups, neither were radiological data from those denying joint symptoms. This does not appear to have meant any significant impact on prevalence spectrum.

The pure prevalence figures of the present survey would *therefore* be *sufficiently representative* to serve as the basis for the following analysis of their implications.

Serology

Data on SSCT and AFT are found in Tables 16 and 17 The proportion of positives is low in comparison with that found in clinical materials. There are no significant age differences between proportions of positives. Males, however have a significantly higher proportion of positives, .3% (13) being SSCT positive, as against 13% (30) for females. The same tendency exists for AFT males 21% (12) positives, females 17% (39) positives. Sex-different titre spectra for LPT have been reported by Valkenburg et al. (1966). This might be one faucet of the male excess mortality Bennett & Burch (1968) found an excess mortality for males with a positive test for rheumatoid factor irrespective of diagnosis.

In the present investigation a strong relationship was found between mortality and positive serology During the observation period of 33 months between mailing the questionnaire and re-examination of age-group 70–74 9 out of 82 died. Out of these 9 persons 8 were seropositives with severe RA disease (Appendix table 5 p. 124).

Table 17 demonstrates the relationship between different titres of SSCT and AFT With rising titre by one test the chance for positivity of the other increases. This has been found by Bennett & Burch (1968) in total populations of Pima and Blackfeet Indians and by Valkenburg et al. (1966) in Great Britain.

The results ! Tables 16 and 17 relating to concordance between SSCT and LPT are in

Table 15. *Prevalence of RA according to different definitions*

Percentages in italics

Age-group (yrs.)	Sex	Total examined[a] Weighted	Total examined[a] Not weighted	1 st examination Clinical Rome criteria ≥3	≥5	≥3 pos. SSCT and X-ray grade 2 for RA	Incomplete X-ray and/or serology lacking	2nd examination New York criteria ≥1	≥2	≥3	4
70–74	M	568	968	12 *2.1*	7 *1.2*	3[b] *0.5*	1	7 *1.2*	7 *1.2*	4 *0.7*	1 *0.2*
	F	1 038		70 *6.7*	47 *4.5*	17[c] *1.6*	5[d]	57 *5.5*	53 *5.1*	31 *3.0*	11 *1.1*
56–60	M	1 134	1 307	34 *3.0*	12 *1.1*	7 *0.6*	2	32 *2.8*	23 *2.0*	17 *1.5*	7 *0.6*
	F	1 601		115 *7.2*	42 *2.6*	15 *0.9*	3	111 *6.9*	83 *5.2*	33 *2.1*	15 *0.9*
42–46	M	1 921	979	17 *0.9*	6 *0.3*	2 *0.1*	1	19 *0.6*	10 *0.5*	2 *0.1*	2 *0.1*
	F	2 002		57 *2.8*	17 *0.8*	11 *0.5*	2	53 *2.6*	43 *2.1*	18 *0.9*	11 *0.5*
31–36	M	1 713	941	6 *0.4*	5 *0.3*	2 *0.1*	0	6 *0.4*	5 *0.3*	4 *0.2*	2 *0.1*
	F	2 159		15 *0.7*	7 *0.3*	1 *0.0*	0	15 *0.7*	14 *0.6*	10 *0.5*	0 *0.0*
Total	M	5 336	4 195	69 *1.3*	30 *0.6*	14 *0.3*	4	57 *1.1*	45 *0.8*	27 *0.5*	12 *0.2*
	F	6 800		257 *3.8*	113 *1.7*	44 *0.6*	10	236 *3.5*	193 *2.8*	92 *1.4*	37 *0.5*

Total RA prevalence 2.7%.
[b] Including 2 not reexamined.
5 not reexamined.
[d] Including 1 person with weighting number 2, and 1 person with SSCT 1/320.

agreement with those reported by Valkenburg (1963) for whole populations. This implies a probably insignificant influence on serological spectrum by the non-rheumatoid population. In the present investigation, total concordance of serological tests was within the RA group 87.4% but within positives 58.3%.

X-ray findings

The distribution of different gradings by sex and age will be found in Table 18. As many as 47% were graded ≥2 for RA, which is definitely higher than the percentages reported by Engel et al. (1966), 11.3% and by Kellgren (1966 1968 *b*) from the Leigh and Wensleydale surveys, 23.5%. For the total age-group 50–59 years, Kellgren & Lawrence (1956) found 35% of males and 41% of females to qualify for X ray grade 1 for RA 5% of males and 12.5% of females fulfilled grade ≥2.

The disparity between data from the present survey and other surveys might imply a definitely higher severity of radiological changes possibly owing to different interpretations of X ray findings. The possibility of more radiological findings in the present survey and/or wider limits for clini-

Table 16. *Results of serological tests (SSCT and AFT) in RA and contrast groups*

Age-group (yrs.)	RA groups SSCT AFT neg.	SSCT neg. AFT pos.	SSCT pos. AFT neg.	SSCT pos. AFT pos.	% pos.		Contrast groups SSCT AFT neg.	SSCT neg. AFT pos.	SSCT pos. AFT neg.	SSCT pos. AFT pos.	% pos.	
I 70–74	48	5	5	6	*17*	64	77	3	1	3	*8*	84
II 56–60	117	5	2	19	*18*	143	140	1	4	1	*4*	146[a]
III 42–46	52	4	—	9	*20*	65	114	—	1	1	*2*	116
IV 31–36	18	1	—	2	*17*	21	108	—	—	—	—	108
Total	235	15	7	36		293	439	4	6	5		454
%	*80*	*5*	*3*	*12*	*20*		97	*1*	*1*	*1*	*3*	

Two refusals not included.

Table 17 *Relation between SSCT and AFT in the RA groups*

AFT titre	SSCT titre Neg.	1/20	1/40	1/80	1/160	1/320	1/640	Total	%	% SSCT positives
Neg.	235	4	2	1	—	—	—	242	83	3
1/40	5	4	1	—	—	—	—	10	3	50
1/80	5	3	8	—	—	—	—	16	6	69
1/160	5	—	4	4	2	—	—	15	5	67
1/320	—	—	—	2	5	—	—	7	2	100
1/640	—	—	—	1	—	—	1	2	1	100
1/1280	—	—	—	1	—	—	—	1	—	100
Total	250	11	15	9	7	—	1	293		
%	86	4	5	3	3		—		100	
% AFT positives	6	64	87	89	100	—	100			

cal RA in other surveys must also be taken into consideration. Most other investigations dealing with this problem have relatively few cases in age-groups comparable with those in the present study and are therefore subject to fairly large sampling errors.

Duration of joint symptoms

One of the advantages of the re-examination of the RA group described on p. 29 was that only persons with long-standing joint symptoms, recorded on two separate occasions, were accepted. Table 19 shows the duration of joint symptoms as reported at the first interview. The high proportion of persons with a long duration of disease is obvious and it increases with age. In the total RA group, 84% had been ill for more than five years.

Steinbrocker groups

The Steinbrocker functional class grouping (Steinbrocker et al., 1949), being a crude measure on function, is demonstrated in Table 20. The distribution towards better function in comparison with that found in hospital series (e.g. Duthie et al., 1964) is apparent. Information on functional capacity from population studies is scarce. Bremner (1961), however reported from the Wensleydale survey that 91% had functional class I–II, which is in accordance with the present investigation.

Diseases other than RA

In practically all RA survey reports, the subjects seem to be considered to suffer from RA alone. To throw some light on this problem, the numbers of diagnoses other than RA in different age-groups are set out in Fig. 11. The analysis was based on 35 clinical diagnoses made on clear-cut symptoms or signs. These diagnoses can be exemplified by cardiac insufficiency diabetes, and leg ulcers, and usually represent long-standing conditions.

Surprisingly many in age-groups 70–74 and 56–60 years, suffered from long-term diseases other than RA. The numbers of diagnoses do not,

Table 18. *Radiological grading for RA*
Weighted numbers

X-ray grade for RA	Age-group (yrs.) 70–74	%	56–60	%	42–46	%	31 35	%	Total Males		Females			
0	18	28	56	39	37	57	5	24	15	26	101	43	116	40
1	9	14	24	17	4	6	2	10	11	19	28	12	39	13
2	14	22	31	22	7	11	8	38	14	25	46	19	60	20
3	12	19	16	11	9	14	3	14	11	19	29	12	40	14
4	11	17	16	11	8	12	3	14	6	11	32	14	38	13
Total	64		143		65		21		57		236		293	

Table 19 *Duration of joint symptoms*

Duration of disease	Age-group, yrs. 70–74	%	56–60	%	42–46	%	31–35	%	Total	%
< 23 mo.	1	*1.5*	9	*6*	9	*14*	2	*10*	21	*7*
2–4 yrs.	1	*1.5*	16	*11*	9	*14*	—	—	26	*9*
5–9 yrs.	18	*28*	29	*20*	8	*12*	11	*52*	66	*23*
10–19 yrs.	12	*19*	32	*23*	19	*29*	7	*33*	70	*24*
> 20 yrs.	32	*50*	57	*40*	20	*31*	1	*5*	110	*37*
Total	64		143		65		21		293	

however increase with increasing severity of RA expressed as radiological progression (Table 21). Significantly higher ($p < 0.01$) proportions of those with X ray grade 0–2 had diagnoses other than RA. Self reported chronic conditions other than RA are also common in the RA group (Table 24 p. 62).

Conclusions

The RA prevalence spectrum is broad, ranging for females from 9.5% classical cases to 3.5% fulfilling ≥ 1 New York criteria for RA. The ratio males/females is 1/3 Even if most of the persons in the RA group have a history of joint disease for several years, a positive serological test for rheumatoid factors is a relatively uncommon finding in the group, especially in comparison with X-ray evidence, which is found in nearly half the RA group. Diseases other than RA are often left out in survey reports but are represented by a considerable number especially in higher age-groups.

Contrast group

Criteria

The principles by which the contrast group was formed are outlined on p. 41 69% of the group were females.

Table 20. *Steinbrocker functional classes*

Steinbrocker functional class	Age-group, yrs. 70–74	%	56–60	%	42–46	%	31 35	%	Total	%
I	2	*3*	5	*3*	1	*2*	4	*19*	12	*4*
II	50	*78*	119	*83*	59	*91*	16	*76*	244	*83*
III	10	*16*	15	*11*	5	*7*	1	*5*	31	*11*
IV	2	*3*	4	*3*	—	—	—	—	6	*2*
Total	64		143		65		21		293	

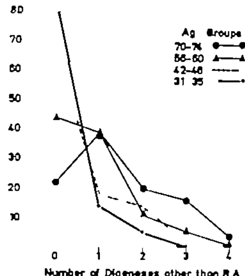


Fig 11 Number of diagnoses of long term diseases other than RA as percentage of total RA persons in each age-group.

It is obviously impossible to achieve a contrast group free of any joint symptoms. On the other hand minor symptoms were acceptable but persons with RA resembling joint syndromes were excluded (Appendix Table 8 p. 127)

The composition of the contrast groups will be seen from Table 22. The majority 74.3% do not fulfill any criteria for RA. Out of the 98 persons fulfilling criteria for polyarthritis, 67 met cri-

Table 21 *Relation between X-ray grading for RA and number of diagnoses other than RA*

Number of persons. Percentages in italics

No. of diagnoses other than RA	X-ray grading for RA: 0	1 2	3–4	Total
0	*37* 51 *44*	*27* 37 *37*	*36* 49 *63*	*100* 137
1 2	*42* 57 *49*	*39* 53 *54*	*19* 25 *32*	*100* 135
3–4	*38* 8 *7*	*43* 9 *9*	*19* 4 *5*	*100* 21
Total	116 *100*	99 *100*	78 *100*	293

Table 22. *Criteria in contrast groups*
Percentages in italics

Age-group (yrs.)	Sex	Fulfilling: No criteria	Clinical criteria for polyarthritis	Clinical criteria for RA only	Combinations of clinical criteria for RA and polyarthritis	Serology: SSCT pos. only	AFT pos. only	SSCT AFT pos.	No tests obtained	Total
I	M	14	5	—	—	—	2	—	—	19
70–74	F	41	16	1	7	1	1	3	—	65
II	M	30	12	—	2	—	1	—	1	44
56–60	F	70	31	—	3	4	—	1	1	104
III	M	31	10	—	3	—	—	—	—	44
42–46	F	56	13	—	3	1	—	1	—	72
IV	M	30	4	—	—	—	—	—	—	34
31–36	F	67	7	—	—	—	—	—	—	74
Total		339 *74.3*	98 *21.5*	1 *0.3*	18 *3.9*	6 *1.3*	4 *0.9*	5 *1.1*	2 *0.4*	456
Persons with pos. SSCT and/or AFT		9 *2.7*	5 *5*	0 *0*	1 *6*					15 *3.3*

terion no. 2 (joint pain). 18 persons fulfilled combinations of clinical criteria for RA and polyarthritis, 16 of them meeting the combination of criterion no. 2 for polyarthritis and no. 1 for RA.

Results of serological tests

By the screening procedures used, the contrast group should consist of persons healthier than a random sample of the whole population of the same ages. It is therefore reasonable to consider that the contrast population would serve as controls for the serological tests, though more adequately selected than, e.g., blood donors.

Relations between SSCT and AFT are shown in Table 23 and age-specified data in Table 22.

Only 3.3% (15 persons) were serologically positive. Unlike the results in the RA groups, the proportions of positives were age-dependent, being 8.3% (7 persons) in age-group 70–74 years and 4.1% (6 persons) in age-group 56–60. The total agreement in both tests (Table 23) was 97.1% but of the few positives, all with low titres, only 2 out of 5 showed concordant results.

Table 23. *Relation between SSCT and AFT tests in contrast groups*

	SSCT titre: Neg	1/20	1/40	1/80	Total		% SSCT positives
Neg.	439	4	2	—	445	*98*	*1.3*
AFT 1/40	—	2	1	—	3	*1*	*100*
Titre 1/80	4	—	1	1	6	*1*	*33.3*
Total	443	6	4	1	454*		
	98	*1*	*1*	—			
AFT positives	*0.9*	*33.3*	*50*	*100*			

* 2 persons refused taking of blood samples.

Serological tests vs. criteria

Nine out of 15 serologically positive individuals did not fulfill any of the clinical New York criteria for polyarthritis or RA (Table 22). Five of the remaining 6 fulfilled only criterion no. 2 for polyarthritis. One single person with positive serology met New York criterion no. 2 for polyarthritis *and* no. 1 for RA. In the contrast group, positive tests for rheumatoid factor were *not* associated with clinically detectable signs of joint disease.

Self reported chronic conditions in contrast and RA groups

One of the measures on health is the number of chronic conditions reported on interview (Purola et al., 1968. US Vital and Health Statistics 1968) in the present investigation being the respondent's answer to question 43 on the re-examination form (p. 132). Maximally two disease or symptoms had to be chosen by the respondents. Table 24 shows percentages of respondents with ≥ 1 chronic conditions. Even when the contrast group was cleared

Table 24. *Percentage reporting > 1 chronic conditions in RA and contrast groups. For the RA groups conditions except joint symptoms are considered*

		Age-group, yrs.				
	Sex	70–74	56–60	42–46	31–35	Total
RA	M	*13*	*42*	*50*	*50*	*40*
	F	*43*	*38*	*14*	*27*	*34*
Contrast	M	*32*	*16*	*11*	*12*	*16*
	F	*14*	*25*	*15*	*19*	*19*

of severely diseased persons, as many as 16% of males and 19% of females answered positively and specifically on this question. A highly significantly greater proportion ($p < 0.001$) of the RA group than of contrasts reported one or two chronic conditions other than RA. The corresponding age-matched figures from Finland (Purola et al., 1968) and the US (Vital and Health Statistics 1968) are twice to three times as high. This could mean not only that contrast groups are definitely healthier than the average population but also that part of the difference could be due to interview methods used. For 40% of male and 34% of female RA persons joint symptoms are accompanied by other subjective chronic conditions which definitely complicate the evaluation of the impact of RA on the life situation.

Conclusions

Persons in the contrast group are not free of joint symptoms, but these are relatively few and mostly represented by joint pain.

It is shown that in the contrast group positive serological tests for rheumatoid factor are rare and highly dependent on age but not on joint symptoms. The presence of subjective chronic conditions is definitely lower than in other comparable investigations, implying that general health in the contrast group is better than in the average population. Physical examination would therefore serve as a satisfactory screening for RA.

Relationship between different sets of criteria for RA

When the new set of criteria for RA was introduced in 1966, their function, relevance, and relationship to the earlier Rome criteria, although theoretically fairly well defined, had virtually not been studied in surveys. Some data are available which indicate that the 1966 RA criteria are stricter (see p. 17).

Table 25 shows the relationship between clinical criteria for polyarthritis and criteria for RA. This table does not include total numbers of examined by both sets of criteria. Characteristics of individuals excluded from the RA group are found in Appendix Table 7 p. 127 and should also be considered, but their influence on the total pattern of relationship is unimportant. Another drawback in the comparisons of sets of criteria is that the initial screening procedure did not consider the New York criteria, except for age-group 31–35.

Some main conclusions can be drawn from Table 25

1 Even if nodules will be found in 23 (47 %) out of 49 individuals fulfilling four criteria for RA and in 25 (23 %) out of 111 fulfilling five clinical criteria for polyarthritis, they were recorded in each cell, irrespective of number of criteria.

2. X-ray changes grade ≥ 2 for RA will be found in 62 (55 %) out of 111 individuals fulfilling five clinical criteria for polyarthritis. These changes, however are recorded in 42 % for four criteria, 42 % for three, 31 % for two, and 38 % for one criterion.

3 Those fulfilling criterion no. 1 for polyarthritis (morning stiffness) appear in greater proportions in the group fulfilling three criteria for polyarthritis (63 %) than two (36 %) and four (16 %). These differences are significant ($p < 0.05$ $p < 0.001$ respectively), which might imply that morning stiffness to some extent is depending on joint pattern. Morning stiffness was recorded in 44 % (one criterion for RA) and 78 % (four criteria for RA). The differences in proportions with morning stiffness between those fulfilling three and four criteria for RA are significant ($p < 0.01$). However the general conclusion could be drawn that the exclusion of morning stiffness from the RA criteria of 1966 was reasonable and that morning stiffness would not contribute any crucial information towards the diagnosis of RA.

4. Of those fulfilling four and five clinical criteria for polyarthritis, 93 % met criterion no. 2 for RA. These sets apparently measure the same parameters.

5 Individuals with a positive SSCT or AFT exist in each summed-up number of clinical criteria for polyarthritis, even if a concentration of SSCT positives (22 %) was found in those fulfilling five. On the other hand, 19 (44 %) out of the SSCT positives were found to fulfill four or more clinical criteria for polyarthritis. Of those fulfilling criterion no. .. (1966) 25 % were serologically positives.

If those fulfilling four criteria for RA are considered to be classical" RA, 8 (19 %) of the SSCT-positive individuals will fall outside that group.

Relationship between certain criteria with reference to age

Age has a considerable influence both on prevalence of RA and on criteria *per se*. The invalidation of conclusions provoked by small numbers is sometimes inevitable.

Fig. 1 demonstrates the average proportions of individuals in different numbers of criteria for polyarthritis fulfilling criterion no. 2 for RA (1966). Figs. 12 and 13 also show ranges of mean percentages. There are two levels, one from one to three criteria, and another from four to five criteria for polyarthritis. The wide range within the low number of criteria is obvious. For criterion no 3 (X-ray grade ≥ 2) the same range within those fulfilling one to four criteria for polyarthritis is noted (Fig. 13).

From clinical work, e.g. Sievers (1965), it is known that a strong relationship exists between

Table 25. *Relationship between different sets of criteria in the RA group. Number of persons.*

	Number of criteria (New York 1966) for								
	Clinical polyarthritis					RA			
	1	2	3	4	5	1	2	3	4
Number	13	42	48	79	111	55	116	73	49
Criterion for polyarthritis (no.)									
1	3	15	30	13	111	24	74	37	38
2	10	42	48	79	111	55	115	73	47
3	—	27	48	79	111	42	108	69	46
4	—	—	18	79	111	20	85	59	44
5	—	—	—	66	111	4	74	56	43
Nodules	2	1	2	8	25	2	6	7	23
Criterion for RA (no.)									
1	13	42	48	77	110	53	116	72	49
2	5	15	19	66	111	2	93	72	49
Pos. SSCT	3	5	1	10	24	—	2	6	35
Pos. AFT	2	2	2	11	34	—	1	4	46
X-ray changes grade > 2 for RA	5	13	20	38	62	—	20	69	49

positive tests for rheumatoid factors and X ray changes. Fig. 14 illustrates this relationship in the present investigation. There is a continuous increase in the rate of SSCT positivity with increasing radiological progression of disease, from 3.4% in grade 0 up to 52.6% in grade 4. This is the same pattern, but *not* the same grading, between positive LFT and X ray grading as that found by Thould & Simon (1966). The greatest interval is between grades 2 (6.7%) and 3 (32.5%), which partly argues against the opinion of Cathcart et al. (1968), who proposed that radiological criteria should be more concerned with discrimination within grades 0–2 than within 2–4. With respect to X-ray grading, positive AFTs were in the present survey distributed largely like the SSCTs.

Mean dilution of SSCT positives (1 = 1/20, 2 = 1/40, etc.) was 2 for X-ray grade 2, 2.7 for grade 3 and 2.2 for grade 4. For grade 0–1 it was 1.1.

Table 26. *Duration of RA symptoms, X-ray grade and number of criteria for RA (1966)*

Number of individuals

Duration of RA (yrs.)	X-ray grade for RA					Number of criteria for RA (1966)			
	0	1	2	3	4	1	2	3	4
> 4	25	5	12	3	2	10	25	8	4
5–9	26	7	16	9	8	12	20	21	13
≤ 10	65	27	32	28	28	33	71	44	32

Duration of disease

Table 26 shows duration of disease, X-ray grade, and number of criteria for RA (1966). An analysis, using a method described by Goodman & Kruskall (1963), showed a significant increase ($p < 0.05$) with increasing duration of RA symptoms. This is in agreement with data found by Thould & Simon (1966), and others. There was, however no significant increase of number of criteria with increasing duration of symptoms.

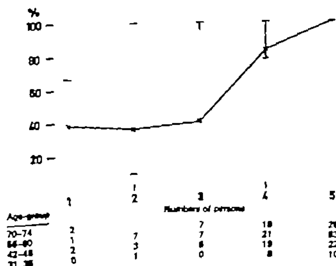
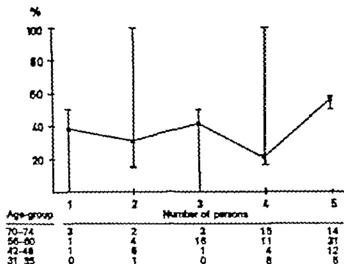


Fig. 12. Average proportions fulfilling criterion no. 2 for RA (NY 1966).



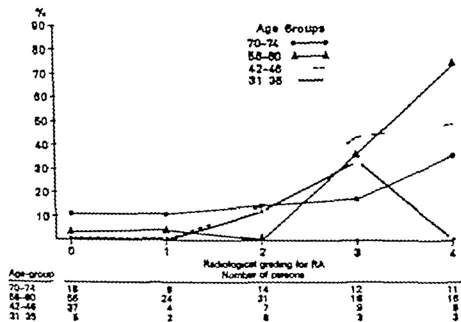
Age-group	1	2	3	4	5
	Number of persons				
70–74	3	2	2	15	14
56–60	1	4	16	11	37
42–46	1	6	1	4	12
31 35	0	1	0	8	6

Fig 13 Average proportions fulfilling criterion no. 3 (X-ray) for RA (NY 1966).

Conclusions

In "Collaborative review of diagnostic criteria for RA (1969) it was stated that the average sensitivity for RA among those fulfilling two New York criteria was 89 As average specificity was 78, the RA criteria could be considered accept able and definitely to delineate RA better than did the criteria for polyarthritis. The same conclusions were drawn by O'Sullivan & Cathcart (1969).

The results of the present investigation confirm that the New York criteria are stricter than the clinical Rome criteria. The overlapping between different groups is still, and should probably be, rather considerable. Morning stiffness does not increase diagnostic exactness when applied to the New York criteria. As regards SSCT positives, 19 % fall outside the four-criteria group (1966). Age means probably a wide scatter in relationship between criteria. With respect to a positive SSCT X-ray grades 0–2 and 3–4 represent different groups. No relationship was found between duration of RA symptoms and X-ray grade or number of criteria for RA (1966).



Age-group	0	1	2	3	4
	Number of persons				
70–74	18	8	14	12	11
56–60	56	24	31	18	16
42–46	37	4	7	9	8
31 35	5	2	8	3	3

Fig 14 Percentages of SSCT positives according to age and radiological progression of RA.

Joint pattern problems. Coexistence of findings

General remarks

In textbooks of rheumatology symmetrical and peripheral joint involvements are described as major features of RA. It is therefore very likely that, because of diagnostic selection, clinical materials of RA will contain more patients with symmetrical involvement and positive tests for rheumatoid factors than will RA groups from a population survey. Even if symmetry were included in the first set of criteria, it was not until 1966 that the pattern of joint involvement was included as criterion no. 2 for RA. The joint score proposed, however, was rendered incomplete because of the exclusion of non-RA joints from the joint pattern. The 1966 criteria were strongly influenced by Lawrence & Wood's (1968) presentation of data on all individuals graded 4 for RA (numbering 11) in the British surveys. These 11 were compared with 44 age- and sex-matched persons in the other four clinical gradings. Six times as many joints were involved in the grade-4 as in the grade-0 group.

When joint pattern is considered, there is, however, need of rigorous definitions of the elements, their sites and combinations, and consequently of symmetry. The situation is, furthermore, complicated by the immense amount of possible combinations of data.

Previous investigations

Principles and problems of analysis of joint pattern are similar for RA and OA. As OA is a more frequent disease, detailed studies of joint pattern are not usually impaired by small numbers. Such studies have been performed by O'Brien et al. (1968). In the New Haven survey they concluded that the second DIP joint of the hand was the most frequent site of OA. In 17.34% of hands OA occurred in ≥ 6 joints. A meticulous analysis of OA symptoms in a rheumatoid and non-rheumatoid population from the British surveys has been performed by Lawrence et al. (1966 *b*). One of their conclusions was that rheumatoids had more pain from OA than had non-rheumatoids with the same grade of OA. This analysis was later supplemented by Lawrence (1969). A description of clinical symptoms in a Swiss population on a joint-by-joint basis was published by Wagenhäuser (1969).

In Report on an enquiry into the aetiological factors, associated with rheumatoid arthritis. Empire Rheumatism Council (1950), joint pattern was considered. Joints were split up not only into peripheral, proximal, and spinal but also into subgroups of joints, such as PIPs and MCPs. Symmetrical total clinical involvement of certain joint groups was regarded as symmetry: for MCPs 59% and PIPs 73%.

Thould & Simon (1966) studied radiological joint involvement and recorded symmetry between joint groups. They noted a great increase of symmetrical X-ray changes with increasing X-ray grade for RA. Sievers (1965) applied a gross classification of joint involvement (hands, feet, etc.). In Engel's et al. (1966) survey symmetrical joint swelling was recorded in 62.3% of the rheumatoid population.

Symmetrical joint involvement in a wider sense was used by Short et al. (1957) and by Ragan & Farrington (1962) who reported 70% and 86% respectively.

Diesner (1962) mentioned symmetry without definition of its content.

The connection between joint pattern and prognosis has been reviewed by Sievers (1965). Laaksonen (1966), in reporting on 544 cases of juvenile RA, recorded a lower functional class among those with involvement of small joints. Duthie et al. (1964) however on the basis of a long-term follow-up of 307 RA patients, using a not strictly defined concept of symmetry concluded that the pattern of joint involvement had no impact on prognosis.

Elements in joint-pattern analysis

From the foregoing presentation of the literature on joint pattern, it is evident that exact definitions of types and extent of joint involvement are necessary in joint-pattern analyses.

An analysis of any joint involvement can comprise both individuals and groups. Measures on joint involvement, especially cumulative, have not been clearly reported. Basic data applied in the analysis of joint pattern are presented in Tables 27 and 28. Except for erosions, gradings other than "present" or "absent" were not used. Joints were classified into "RA" or "Non-RA" according to New York criterion no. 2 for RA. For each separate joint, maximally five clinical and six radiological parameters could be recorded simultaneously. The retainment of the initial basis for recordings would have made the analysis unwieldly. A reduction and concentration to the above-mentioned joint groups seemed reasonable. Osteoporosis, difficult to assess, was excluded.

Findings in single joints

In transferring information from a single-joint to a joint-group basis, errors will be introduced. When a clinical finding of swelling in *one* and of erosion in *another* joint are brought together into a joint-group, this joint-group will show more pathological signs than will the individual joints in the group. From the viewpoint of joint pattern, this is a disadvantage, but from a functional viewpoint it is a definite advantage.

To form an idea of the impact on the final data of this first concentration of original information, some data recorded on a single-joint basis were studied. Joint groups MCP 2–5 right hands, in age-group 56–60, were chosen as representative.

Table 27 *Variables in joint pattern analysis*

Clinical	Radiological
Swelling	Reduction of joint space
Tenderness	Erosion grade 1
Pain on motion	Erosion grade 2 3
Limitation of movement	Erosion grade 4–5
Subluxation or luxation	Subluxation or luxation
Ankylosis	*Ankylosis*
	Osteoporosis
	Osteo-arthrosis
	Bone cysts
	Judgement impossible

The result of this recording is presented in Fig. 15

It will be seen that pain and/or tenderness are the predominating clinical findings, being more prominent in MCP 2 and 3 than in 4 and 5 ($p < 0.001$). Analogous findings are recorded for swelling ($p < 0.001$). X-ray changes, here defined as erosions, are admittedly more common in MCP 2 but the differences between MCP 2 and the other MCPs are not significant.

Erosions were found in a total of 65 joints, but only in 45 of them was pain recorded, the difference being greatest for MCP 2, though not statistically significant. One explanation of the great difference between numbers of clinical symptoms in MCP 2–3 and in MCP 4–5 might be the greater strain on MCP 2–3. The co-existence of pain/tenderness and X-ray changes might, statistically be purely coincidental for MCP 2, but for MCP 3–5 it differs significantly from the expected co-existence ($p > 0.05$).

Erosions and pain

An analysis was made in order to obtain information on the co-existence of erosions and pain and,

Table 28. *Joint groups*

Joint group number	RA joints	X-ray present (+) absent ( )	Joint group number	Non RA joints	X-ray present ( ) absent (–)
1	Shoulder	–	1	CMC 1 hand	
2	Elbow	–	2	DIP 1 5 hand	
3	Wrist CMC, IC, RC	+	3	DIP 2–4 foot	
4	MCP 1 5 hand	+	4	DIP 1 foot	
5	PIP 2–4 hand	+	5	MTP 1 foot	
6	MTP 2 5 foot		6	Hip	
7	PIP 2–4 foot		7	Sternoclav joint	–
8	Ankle		8	PIP 5 hand	
9	Knee		9	PIP 5 and DIP 5 foot	

Number of Persons

Swelling
Tenderness and/or pain
Tenderness and/or pain + swelling
X-ray changes*
X-ray changes + pain and/or tenderness
X-ray changes + swelling
*Erosions only

MCP 2 3 4 5
Right Hand

Fig 15 Clinical and radiological data for MCP joints 2–5, right hands, age-groups 56–60 yrs (n 143).

on the other hand, differences between joints in this respect. Table 29 shows differences between proportions of bilateral pain/tenderness found in the presence of bilateral erosions.

The general conclusion can be drawn that the proportion of painful joints was higher for RA than for non-RA joints in the presence of erosions. PIPs of feet had significantly less pain than other RA joints, when bilateral erosions were present.

Table 29 *Differences between percentage proportions with bilateral pain/tenderness of some joint groups with bilateral erosions grades 1–5*

Joint group	No. with bilateral erosions	No. with bilateral pain/tenderness of those with bilateral erosions	RA joints: Hands PIP 2 5	RA joints: Feet MTP 2–5	RA joints: Feet PIP 2 5	Non-RA: Hands CMC 1	Non-RA: Hands DIP 1 5	Non-RA: Feet DIP 1	Non-RA: Feet MTP 1
RA									
Hands									
MCP 1 5	49	37	26	−0.4	76	66	47	69	33
PIP 2–5	32	16		−26	50*	41	22	44	7
Feet									
MTP 2 5	58	44			76	67	48	70	33
PIP 2–5	13	0				−9	−28	−6	−43
Non-RA									
Hands									
CMC 1	11	1					−19	3	−34
DIP 1 5	32	9						22	−15
Feet									
DIP 1	16	1							−37
MTP 1	14	6							

Similar calculations were also made for the individuals with only right-sided or left-sided erosions, but here no differences could be found between separate RA and non-RA joints with respect to the proportion of painful erosions.
This also held true when only erosions grade 2 or higher were considered. Bilateral involvement, therefore, seems to separate RA and non-RA joints in this respect. The influence of age was also studied by forming two age-ranges, one "old" 70–74 plus 56–60, and one "young" 42–46 plus 31–35. No statistical differences were found between the age-ranges with respect to proportions of painful identical joints with erosions.

In the "old" age-range a significantly smaller proportion of painful erosions was found in the non-RA than in the RA joints. In the "young" age-range, however, this difference could not be statistically established.

This might imply that non-RA joints with erosions are less painful when degenerative joint changes are present. When these degenerative joint changes are few or absent, as in young RA persons, the ratio pain/erosions is similar for any joint.

As bilaterally involved joints generally have a higher degree of radiological destruction, similar calculations as found in Table 29 were also made, excluding grade-1 erosions, but this did not influence the pattern of differences between joints.

Joint involvement and pattern Exemplified proposals for terms

The description of joint pattern is sometimes quite vague. In order to create some well-defined conceptions, applicable to descriptions of joint pattern, some suggestions for terms will be made here.

Clinical involvement "SCIP"

The basis for the analysis in this section is the joint group. The applied measure of joint involvement is the age-specified proportion of total joints with a certain clinical finding. *Specified Clinical Involvement Percentage* (*SCIP*) is a long but adequate designation of this measure, which can be expressed as a figure for a specified type of clinical involvement, e.g. swelling, for *groups of individuals* (group SCIP) or individuals (individual SCIP). For clinical involvement, group SCIP is illustrated in Fig. 16. For RA joints, pain is the predominating finding and subluxation and ankylosis are seldom found. The age differences, less apparent for RA joints, are obvious for non-RA joints, in which clinical findings, with the exception of swelling and ankylosis, show a considerable increase with age.

Accordingly for "typical" RA the specificity of *total* limitation, *total* joint swelling, etc., decreases with age.

Radiological involvement "SRIP"

The general considerations as regards the background of terms is analogous with those under Clinical Involvement. *Specified Radiological Involvement Percentage* (*SRIP*) can, as for clinical involvement, be expressed as a figure for a specified type of radiological involvement, e.g. for erosions grade 1 as illustrated in Fig. 17.

On comparison with Fig. 16, it will be seen that radiological changes are generally more uncommon than clinical ones. Erosions of grade 1 are three times as common as those of grade 4–5. One important finding is that non-RA joint" erosions, even of severe grades, are not uncommon and increase with age. This also clearly implies that radiological diagnosis of RA *must* be less strict for higher ages. The number of OA changes increases considerably with age, even in non-RA joints.

Total joint involvement "TOCIP TORIP"

A measure of total joint involvement would sometimes be convenient. Such a measure can be formed for a group or for an individual by adding, on one hand, the different SCIPs and, on the other the different SRIPs. The terms *Total Radiological Involvement Percentage* (TORIP) and *Total Clinical Involvement Percentage* (TOCIP) are thus formed. In Table 30 these terms are applied to RA joints and non-RA joints, and OA changes are listed separately. The influence of age is thus more clearly seen.

Symmetry "SYSCIP SYSRIP"

As for the other components in joint pattern, the term symmetry needs to be precisely defined.

For clinical use, *Specified Symmetrical Clinical Involvement Percentage* (SYSCIP) might be convenient. It means the proportion (as a percentage) of *persons* in a material who for a specified change (e.g. swelling) have manifested symmetrical involvement of joints or joint groups. A prerequisite is that components (clinical and radiological findings, joints and joint groups) are recorded in a uniform way in the whole group. For a given type of involvement for all joints, symmetrically and asymmetrically involved persons are summed up. These sums are transformed from a quotient to a percentage of symmetrical persons. This measure (SYSCIP) is used in Fig. 19. The symmetry patterns for RA joints do not show any particular differences between age-groups, except in ankylosis in which recordings are few. For non-RA joints, clinical findings lack a consistent pattern.

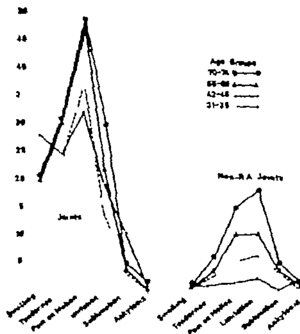


Fig. 16. Specified Clinical Involvement Group Percentage (SCIP) for age-groups and RA/non-RA joint groups

%

Age Groups
70-74
56-60
42-48
31-35

RA Joints

Non-RA Joints

33 8 → ← 28 4

Age-group	Red. Joint Space	Erosion Grade 1	Erosion Grade 2-3	Erosion Grade 4-5	Ankylosis	Subluxations	O.A.	Red. Joint Space	Erosion Grade 1	Erosion Grade 2-3	Erosion Grade 4-5	Ankylosis	Subluxations	O.A.
	Number of observations													
70-74	252	173	107	41	39	132	230	132	29	85	14	33	69	303
56-60	270	8	177	86	80	95	354	96	108	64	2	81	78	868
42-48	136	66	42	38	30	45	18	75	44	30	1	5	23	120
31-35	48	60	27	8	12	0	3	9	12	7	2	1	2	77

Fig. 17. Specified Radiological Involvements Percentage (SRIP) for age-groups and RA/non-RA joint groups. Proportion of joints with X-ray changes.

Table 30 *Total joint involvement. Added proportions* (%)

Age-group yrs.	Total clinical involvement percentage (TOCIP) Clinical		Total radiological involvement percentage (TORIP) X-ray[4]		OA changes	
	RA joints	Non RA joints	RA joints	Non RA joints	RA joints	Non RA joints
I 70–74	*137*	*49*	*67*	*52*	*23*	*34*
II. 56–60	*123*	*32*	*39*	*27*	*16*	*28*
III. 42–46	*96*	*22*	*36*	*20*	*17*	*13*
IV 31 35	*114*	*10*	*46*	*15*	*4*	*6*

With the exception of OA changes.

As far as radiological symmetry is concerned, analogous definitions and terms should be used. *Specified Symmetrical Radiological Involvement Percentage* (SYSRIP) is demonstrated in Fig. 20. An increasing SYSRIP with increasing grade of erosions is noted for all age-groups. For age group 56–60 SYSRIP increases from 22% (erosion grade 1) to 43% (erosion grade 4–5.) The homogeneity of SYSRIP irrespective of age, is obvious for RA joints. For non-RA joints, the patterns are not uniform and are difficult to interpret. Figures for ankylosis are high but founded on few observations. As congenital ankylosis of the PIP of the fifth toe is common, this joint is not included in Fig. 20

SYSCIP and SYSRIP can be used not only for a specific change, as was shown earlier but also for a specific joint or joint group. Differences between SYSCIP and SYSRIP for a specific joint can also be calculated. Such a calculation showed that for age-group 56–60 this difference was 28% for MCP 1–5 of hands but only 8% for MTP 2–5 This implies that radiological involvement of feet produces less prominent clinical findings and/or that these findings are more difficult to diagnose clinically

Total joint pattern in the RA group

The detailed Tables 31 and 32, in which clinical and radiological findings are presented on a joint by-joint percentage basis, contain many figures which might make them difficult to interpret. But they illustrate the data volume that is necessary even in a limited joint-pattern analysis. Schemes could be arranged by sex and age for more detailed comparisons. Each cell represents percentages of 586 joints or joint groups. As an example, it will be found in Table 32 that 21% of erosions grade 4–5 occur in PIPs of hands, and 14% in MTPs of feet 18% of the OA changes occur in DIPs of hands, but as much as 54% of the DIPs show OA changes.

For clinical findings (Table 31), only 13% of joint pain appeared in the MCPs of hands but 60% of the MCP joints were painful.

As regards subluxation, 29% occurred in MTP 1, but only 20% of the first MTPs were subluxated.

Cumulation

An analysis of joint pattern would be incomplete without a study of the number of joints involved. This cumulative process with involvement of several joints is a characteristic of RA, as emphasized in the 1966 criteria.

One way to study cumulative joint patterns is by using clearly defined specified changes in specified joints groups (RA vs. non RA joints).

The following specified cumulative joint patterns were thus constructed. Joint grouping was done according to Table 28 p. 67 Cumulative joint patterns:

1 Radiological OA changes in non-RA joints.
2. Radiological OA changes in RA joints.
3 Radiological signs of RA[1] in non-RA joints.
4 Radiological signs of RA[1] in RA joints.
5 Clinical findings[2] in non-RA joints.
6. Clinical findings[2] in RA joints.
7 Pain and/or tenderness in non-RA joints.
8. Pain and/or tenderness in RA joints.

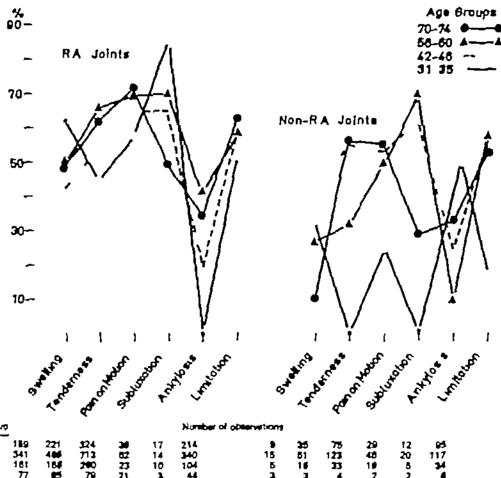
In the calculations, the joint or the person can form the basis. Both aspects will be considered.

Cumulation in RA and OA joints. The joint as the unit

In the following discussion it must be noted that, for a certain change, the number of symmetrical plus the number of asymmetrical individuals does

Reduction of joint space, erosions grade 1 5, subluxation, ankylosis.

Swelling, subluxation, ankylosis, limitation of movement.



Age group	Number of observations											
70–74	189	221	324	38	17	214	9	35	75	29	12	95
56–60	341	486	713	62	14	340	15	61	123	48	20	117
42–46	161	168	290	23	10	104	5	16	33	18	5	34
31–35	77	85	79	21	3	44	3	3	4	2	2	8

Fig. 19 Specified Symmetrical Clinical Involvement Percentage (SYSCIP). Proportion (%) of symmetrical persons for some clinical parameters distributed by age-group and RA/non-RA joint groups.

not equal the total number of individuals. For a certain change, a person might have symmetrical involvement of *one* joint and asymmetrical of *another* This aspect, though being part of a joint pattern analysis, will not be discussed further here.

Fig. 21 illustrates cumulative pattern for OA changes in RA and non-RA joints. The figures refer to *joints* with OA changes in all age-groups.

The analogous curves for radiological RA changes are plotted in Fig. 22. These curves could be interpreted as demonstrating that cumulative patterns for OA and RA changes in an "RA syndrome group are quite different. The cumulative patterns for OA changes are similar for RA and non-RA joints and for RA changes in OA joints. For RA joints with RA changes, 50 % of the symmetrical changes appear in five joints or more, as against 42.5 % of the assymmetrical.

Data in Figs. 21 and 22 also imply that OA changes contribute relatively little to the signs in this screened RA group.

In Fig. 23 in analogy with Figs. 21 and 22, are shown the cumulative patterns of pain and/or tenderness. Quite different patterns for OA and RA joints are seen with much more total pain in multiple joint involvement. For OA joints, 21.7 % of symmetrical pain occurs in three or more joints, as against 84.5 % for RA joints. Definitely less pain in five RA joints is found for asymmetrical (14.4 %) than for symmetrical pain (51.5 %). However the increasing probability of

Table 31 *Joint pattern of clinical findings (percentages)*

293 × 2 = 586 joints or joint groups in every sector. For explanation, see text p. 72

RA

				Hand		Foot			
	Shoulder	Elbow	Wrist	MCP 1 5	PIP 2–4	MTP 2 5	PIP 2–4	Ankle	Knee
Joint number ...	1	2	3	4	5	6	7	8	9
Clinical findings									
Swelling	**3** 7	**6** 11	**10** 19	**30** 57	**11** 20	**7** 14	**0** 0.7	**16** 30	**14** 26
Tenderness	**19** 53	**4** 12	**8** 23	**16** 44	**7** 18	**17** 48	**2** 4	**8** 22	**10** 27
Pain on motion	**15** 66	**6** 29	**10** 45	**13** 60	**8** 36	**8** 57	**3** 12	**12** 53	**13** 55
Sublux. or luxation	**0** 0	**1** 0.7	**1** 1	**16** 10	**11** 7	**28** 19	**0** 0	**4** 3	**1** 0.5
Ankylosis	**1** 0.2	**0** 0	**5** 0.9	**5** 0.9	**7** 1	**8** 1	**23** 4	**5** 0.5	**3** 0.5
Limitation	**15** 39	**5** 12	**11** 29	**8** 21	**7** 19	**6** 16	**12** 31	**7** 19	**3** 9

Boldfaced figures refer to clinical findings
Thin figures refer to joints or joint groups

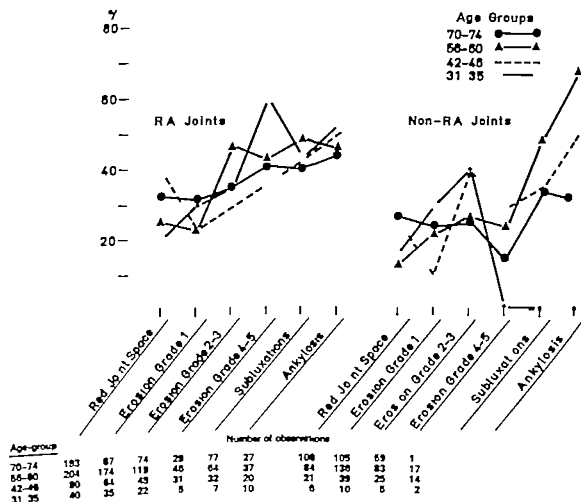


Fig 20. Specified Symmetrical Radiological Involvement ... sons for some radiolor ... but
Percentage (SYSRIP). Proportion (%) of symmetrical per ... group and RA/non-F

on-RA

and			Foot								Total nos. of joints with changes
MCI	DIP 1 5 2		DIP 2–4 3		DIP 1 4		MTP 1 5		Hip 6		
1	2	4	0	0	0	0.2	1	2	0	0.2	1 121
5	3	7	0	0	0	0.7	4	12	0	0	1 620
7	3	15	0	0	1	3	6	25	2	10	2 665
0.7	7	5	0	0	1	0.5	29	20	0	0.2	393
0	10	2	7	1	16	3	7	1	6	1	103
0.2	5	14	1	2	3	7	12	31	5	12	1 517

symmetrical involvement with increasing number of joints involved, must also be considered.

Cumulation in RA and OA joints. Individual and criteria bases

In Figs. 18, 24 and 25 are shown the cumulative patterns for typical radiological RA changes, on the basis of individuals fulfilling one to four of the 1966 criteria for RA. It should be noted that here non-RA joints are fewer than RA joints.

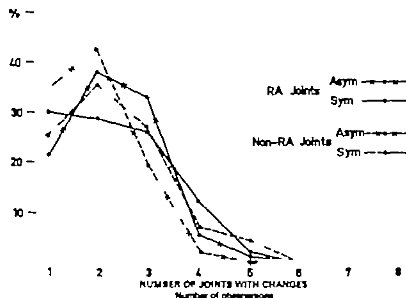
Although cumulative patterns in non-RA joints for those fulfilling three and four New York criteria are fairly similar (Fig. 25), great differences are noted for RA joints in those fulfilling four criteria, implying a pronounced multilocular involvement.

The corresponding data for pain/tenderness are found in Tables 26 and 27. For non-RA joints, striking similarity is found in pain cumulative patterns, irrespective of the number of criteria.

The pain cumulative patterns for RA joints are shown in Fig. 27. There are some, but not very pronounced, differences between groups fulfilling different numbers of criteria. The mean number of painful RA joints among those fulfilling one New York criterion is 2.85 and increases gradually to 4.94 for those fulfilling four criteria.

The interpretation of the results in Figs. 26 and 27 could be that, with respect to RA and non-RA joints, the 1966 RA criteria would, even to the patient, represent a logical definition.

Several patterns were constructed by adding age



	1	2	3	4	5	6	7	8
			NUMBER OF JOINTS WITH CHANGES					
			Number of observations					
RA								
Asym.	75	134	117	20	8	0	0	0
Sym	89	66	60	28	5	0	0	0
Non-RA								
Asym.	118	142	66	8	0	0	0	
Sym	84	118	80	24	18	0	0	

Fig. 21. Radiological OA. Proportions of number of joints with changes. All age-groups.

Table 32. *Joint pattern of X-ray changes (percentages)*
293 2–584 joints in each joint group.

	RA								Non RA		
	Wrist			Hand		Foot			Hand		
	CMC	IC	RC	MCP 1 5	PIP 2–5	MTP 2–5	PIP 2 5	Ankle	CMC1	DIP 1–5	DIP 2–4
Joint number		3		4	5	6	7	8	1	2	3
Radiological findings											
Reduction of joint space	*11 18*	*11 19*	*10 15*	*18 25*	*4 7*	*8 13*	*3 5*	*8 13*	*7 11*	*8 13*	*1 2*
Erosion grade 1	*4 6*	*5 7*	*6 8*	*11 13*	*8 11*	*11 15*	*7 10*	*5 7*	*6 8*	*12 16*	*5 7*
Erosion grade 2 3	*5 5*	*3 3*	*7 7*	*14 14*	*13 13*	*16 16*	*4 4*	*2 2*	*6 6*	*9 9*	*1 1*
Erosion grade 4–5	*2 0.7*	*3 1*	*18 7*	*19 7*	*21 8*	*14 5*	*1 0.5*	*0 0*	*4 1*	*4 2*	*0 0.1*
OA	*4 13*	*6 19*	*5 17*	*11 33*	*8 26*	*5 8*	*2 5*	*4 12*	*8 25*	*18 54*	*2 3*
Subluxation	*0 0*	*0 0*	*3 2*	*17 12*	*7 3*	*23 17*	*9 7*	*1 1*	*2 2*	*5 4*	*3 4*
Ankylosis	*11 6*	*18 10*	*3 2*	*1 0.5*	*1 0.6*	*2 1*	*2 1*	*7 4*	*0 0.1*	*1 0.3*	*3 2*
No information	*0 0*	*0 0*	*3 1*	*0 0*	*0 0*	*1 0.3*	*6 2*	*1 0.3*	*0 0*	*1 0.3*	*69 27*

Boldfaced figures refer to radiological findings.
Thin figures refer to joints or joint groups

to the basis of the classification used above. The finding was a slight, but not general, tendency towards involvement of more joints in elderly age-groups. This finding is exemplified in Fig. 28.

Proposed terms for cumulation
MENURAJ MENUCLIJ"

Terms have earlier been proposed for some aspects of joint pattern. It is obvious that the number of joints affected is an important part of

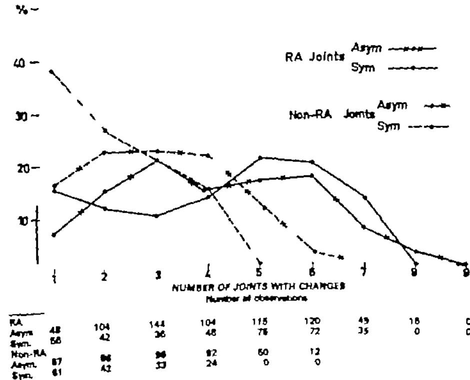
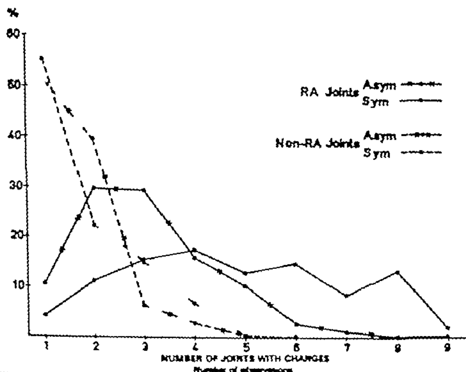


Fig. 22. Radiological RA. Proportions of number of joints with changes. All age-groups.

...ot IP1	MTP1 5		Hand PIP5 8		Foot PIP5 DIP5 9		Total nos. of joints ...th changes
3	5	9	2	3	2	3	949
10	4	6	3	4	5	7	810
5	8	8	4	4	3	4	592
0.5	4	1	5	2	0	0.1	224
14	18	54	6	17	0	3	1 793
0.5	20	14	6	3	3	2	429
0.5	0	0	1	0.5	49	26	311
1	1	0.5	1	0.3	14	5	230

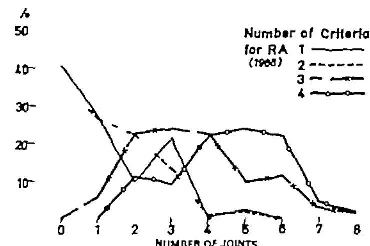
a joint-pattern analysis. Besides a graphical demonstration, it is evident that the mean number of involved joints is a good measure of dissemination of disease. *MEan NUmber of RAdiologically involved Joints* (MENURAJ) and *MEan NUmber of CLinically involved Joints* (MENUCLIJ) are the proposed terms, expressed as figures with standard deviations of the mean. These measures are illustrated in Figs. 24–28. To serve as exact descriptions useful in comparisons of patient and population data, these terms must be specified in some respects.

(*a*) Individual or joint basis.
(*b*) Age.
(*c*) Type or types of joint involvement.
(*d*) Joints or joint groups.
(*e*) Set of criteria.



	Number of observations								
RA									
Asym	93	186	183	100	86	8	7	0	0
Sym	1	1 [illegible] 4	186	178	130	50	84	36	8
Non RA									
Asym.	73	68	9	4	0				
Sym	64	28	8	8	0				

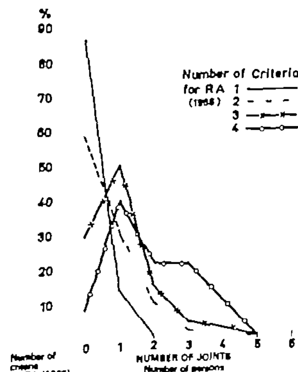
Fig. 23 Pain and/or tenderness. Proportions in number of joints with pain/tenderness. All age-groups.



No. of criteria for RA (1966)	0	1	2	3	4	5	6	7	8	MENURAJ*	SD
	Number of persons										
1	21	14	8	11	0	1	0	0	0	1 11	1 123
2	40	30	25	16	1	2	0	0	0	1 23	1 196
3	0	4	16	17	16	7	8	2	1	3 61	1 699
4	0	0	6	5	12	13	12	6	1	4 72	1 522

*see text

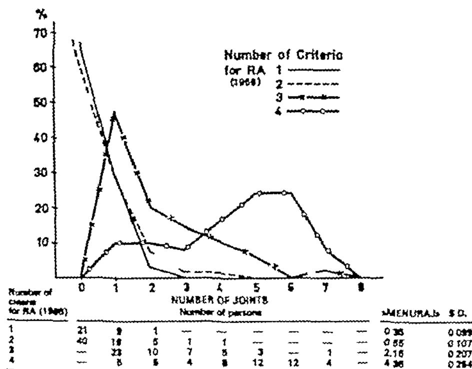
Fig. 23 Percentage distribution of individuals with *asymmetrical radiological RA changes* in different numbers of RA joints.



Number of criteria for RA (1966)	0	1	2	3	4	5	6	*MENURAJ	SD
	Number of persons								
1	19	3	—	—	—	—	—	0 14	0 075
2	35	19	6	1	—	—	—	0 85	0 094
3	14	24	7	2	1	—	—	1 00	0 130
4	3	15	8	8	4	—	—	1 87	0 [illegible]

*see text

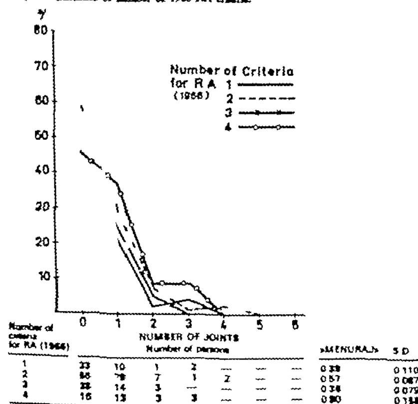
Fig. 24 Percentage distribution of individuals with *symmetrical radiological RA changes* in different numbers of *non-RA joints*. Influence of number of 1966 RA criteria.



Number of criteria for RA (1966)	0	1	2	3	4	5	6	7	8	»MENURA»*	S.D.
	Number of persons										
1	21	9	1	—	—	—	—	—	—	0.35	0.099
2	40	18	5	1	1	—	—	—	—	0.55	0.107
3	—	23	10	7	5	3	—	1	—	2.16	0.207
4	—	5	5	4	8	12	12	4	—	4.36	0.264

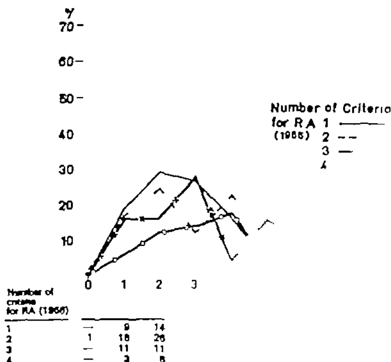
*see text

Fig. 23 Percentage distribution of individuals with symmetrical radiological *RA changes* in different numbers of *RA joints*. Influence of number of 1966 RA criteria.



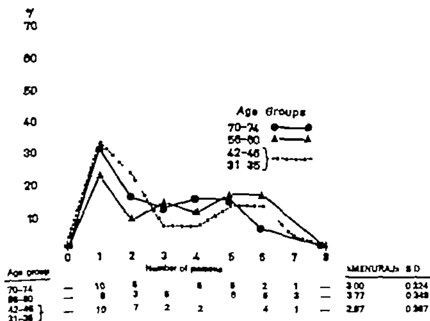
Number of criteria for RA (1966)	0	1	2	3	4	5	6	»MENURA»	S.D.
	Number of persons								
1	23	10	1	2	—	—	—	0.38	0.110
2	85	78	7	1	2	—	—	0.57	0.087
3	28	14	3	—	—	—	—	0.34	0.079
4	16	13	3	3	—	—	—	0.80	0.138

Fig. 24 Percentage distribution of individuals with symmetrical *pain/tenderness* in different numbers of *non-RA joints*. Influence of number of 1966 RA criteria.



Number of criteria for RA (1966)	0	1	2
1	—	9	14
2	1	18	26
3	—	11	11
4	—	3	8

Fig 37 Percentage distribution of individual metrical pain/tenderness in different number joints. Influence of number of 1966 RA criteria.



Age group	0	1	2	3	4	5	6	7	8	[illegible]	SD
70–74	—	10	5		5	5	2	1	—	3.00	0.224
[illegible]–60	—	8	3	6		6	5	2	—	3.77	0.248
42–46 } 31–35 }	—	10	7	2	2		4	1	—	2.87	0.287

Fig 28 Perce[illegible] tion of indiv[illegible] metrical radiol[illegible] changes in RA [illegible] fluence of the age [illegible] those fulfilling three [illegible] four criteria for RA

General conclusions on joint pattern analysis

When comparing joint patterns between populations both from surveys and hospitals and in therapeutic trials, simple and generally applicable but precisely defined terms are rarely used. A set up of such terms is proposed, which considers the site and type of involvement, symmetry and cumulation (spread of involvement). They can be based on joints or on individuals, as well as on groups of individuals, and can also be applied in describing joint pattern of single individuals.

The separation of joints into a RA and a non-RA group is a great advantage in delineating the RA syndrome. In no age-group, however are changes limited to RA joints. For several measures this lack of stringency increases with age.

Functional capacity and RA

In epidemiological surveys of RA, data on functional capacity are scarce (Acheson et al., 1969 Bremner 1961 Swanson et al., 1968). Even in clinical materials a more detailed analysis of functional capacity together with other disease parameters is seldom reported (Tiselius, 1969). Sievers (1965) found a lower functional capacity in seropositives than in seronegatives. The ultimate goal, namely to describe adequately a patient's functional capacity as a single but composite index is, in fact, unattainable (Mainland, 1967). The analysis of changes in function and other parameters has been the object mainly of therapeutic trials and will not be dealt with. Sokolow et al. (1962) proposed a scheme for analysis of physical disability in order to form a disability index. Manheimer et al. (1960) based functional capacity for disabled on 1) hand–arm activities, 2) standing, walking, and climbing activities, 3) lifting and carrying activities. Functions were classified as "normal" "moderately restricted" or "severely restricted"

Measures of disease progression

Eight measures were applied in the present investigation, for application in an interrelationship analysis. On the basis of clinical experience, every single item was split up into three parts (*a*) no or *slight*, (*b*) *moderate*, (*c*) *severe* abnormalities.

1 *Index of deformity* Twelve separate deformities, whether bilateral or not, were recorded (p. 131). Every deformity recorded was given value 1 Index of deformity is the sum of the number of recorded deformities. Maximum value 12.

( ) Value 0 = No deformities.
(*b*) Value 1–2 = Moderate number of deformities.
(*c*) Value 3–12 = Severely deformed.
Highest recorded value 11

2. *Index of arm–hand disablement* Values for 17 separate functions, where severely impaired function was given more weight in the summing up (p. 133). Maximal value 136.

(*a*) Value 0–6 = Adequate function.
(*b*) Value 8–16 = Moderate impairment.
(*c*) Value 18–136 = Severe impairment.
Highest recorded value 136.

3 *Index of leg-function disablement* Values for 9 separate functions were graded as for arm–hand functions and summed up (p. 133). Maximal value 72.

( ) Value 0–6 = Adequate function.
(*b*) Value 8–16 = Moderate impairment.
(*c*) Value 18–72 = Severe impairment.
Highest recorded value 72.

4 *Index of pain.* Values for both pain and tenderness (present or absent) in each joint group were summed up. No weighting was applied. Maximal value 60.

(*a*) Value 0–9 = No or slight pain.
(*b*) Value 10–19 = Moderate pain.
(*c*) Value 20–60 = Severe pain.
Highest recorded value 50.

5 *Index of limitation of movement.* Values for limitation were recorded for each joint group and summed up. Maximal value 30.

(*a*) Value 0–3 = No or slight limitation
(*b*) Value 4–9 = Moderate limitation
(*c*) Value 10–30 = Severe limitation.
Highest recorded value 23

6. *Steinbrocker functional class.*

(*a*) Value 1 = No or insignificant impairment of general functional capacity
(*b*) Value 2 = Moderate impairment of general functional capacity
(*c*) Value 3–4 = Severe incapacity
Highest recorded value 4

7 *Respondent's subjective assessment of disease troubles.*
Respondent's answer on item 15 in the re-examination form (p. 131)

Table 33. *Measures of RA progression by age-groups (mean values)*[a]
Weighted numbers

Age-group, yrs.	Indices on impairment: Deformity	Hand-function	Leg-function	Pain	Limitation	Steinbrocker functional class	Grade of subjective disease troubles	Grade of radiological progression
70–74	2.1 ± 0.5	13.1 ± 5.6	15.6 ± 4.1	16.9 ± 2.4	7.7 ± 1.3	2.2 ± 0.2	3.6 ± 0.3	1.8 ± 0.4
56–60	1.7 ± 0.4	10.0 ± 2.6	10.2 ± 2.4	15.6 ± 1.4	5.2 ± 0.9	2.1 ± 0.1	3.4 ± 0.2	1.4 ± 0.2
42–46	1.2 ± 0.5	4.1 ± 2.0	3.3 ± 1.8	11.5 ± 2.2	3.3 ± 1.1	2.1 ± 0.1	2.9 ± 0.3	1.2 ± 0.4
31–35	1.4 ± 1.0	4.1 ± 2.3	2.0 ± 1.9	10.8 ± 2.3	3.5 ± 1.6	1.9 ± 0.2	3.0 ± 0.4	1.9 ± 0.6

[a] 95 % confidence limits of the means.

(*a*) Alternatives 1–2 = Slight subjective disease troubles.

(*b*) Alternatives 3–4 = Moderate subjective disease troubles.

(*c*) Alternatives 5–6 = Severe subjective disease troubles.

Highest recorded value 6.

8. *Radiological stage* The grading 0–4 (p. 30) was used.

(*a*) Grade 0 = No radiological signs of RA.

(*b*) Grade 1–2 = Moderate destructive changes of RA type.

(*c*) Grade 3–4 = Severe radiological changes.

Highest recorded value 4.

The mean values of these eight indices for each age-group are set out in Table 33 It will be seen that even if mean functional capacity by several measures increases significantly with age, three items are not significantly changed, namely mean grades of subjective disease troubles, radiological stage and Steinbrocker's functional class. Of 6 functional measures, one alone, namely Steinbrocker's class, does not show progress with age, and could therefore be judged as an unsatisfactory measure for classifying a person's functional capacity

The subjective grading of disease troubles does not increase with age. This probably implies a personal adaptation to objectively poorer health in higher ages, as reported by several authors, and found in the survey of the literature on selection (Table 1 p. 13).

Relationship between functional indices and radiological and serological data

In the correlation analysis, the classified values were applied, using Olivetti Programma 101 desk calculator Table 34 shows the correlation coefficients between five functional indices and a positive SSCT and/or AFT In this and the subsequent tables, figures for age-group 31–35 years are too small to allow any meaningful conclusion. The correlation coefficients increase with decreasing age.

Table 34 *Positive SSCT and/or AFT (correlation coefficients)*

Index	Age-group, yrs. 70–74	56–60	42–46	31–35
Deformity	0.365	0.526	0.686	−0.032
Arm disablement	0.126	0.381	0.647	0.091
Leg disablement	−0.021	0.153	0.406	−0.198
Pain	0.072	0.130	0.690	−0.203
Limitation of movement	0.352	0.523	0.792	0.167

Table 35 *Radiological stage (correlation coefficients)*

Index	Age-groups, yrs. 70–74	56–60	42–46	31–35
Deformity	0.662	0.513	0.557	0.373
Arm disablement	0.317	0.273	0.429	0.273
Leg disablement	0.141	0.079	0.264	0.032
Pain	0.200	0.266	0.547	0.158
Limitation of movement	0.518	0.629	0.773	0.404

Table 36. *Subjective disease troubles (correlation coefficients)*

Index	Age-groups, yrs. 70–74	56–60	42–46	31 35
Deformity	−0.102	0.185	0.315	0.772
Arm disablement	0.348	0.423	0.535	0.209
Leg disablement	0.334	0.213	0.421	0.113
Pain	0.417	0.388	0.625	−0.155
Limitation of movement	−0.231	0.198	0.396	0.458

Table 37 *Steinbrocker functional class (correlation coefficients)*

Index	Age-group, yrs. 70–74	56–60	42–46	31 35
Deformity	0.076	0.208	0.252	Calculations not meaningful
Arm disablement	0.686 **	0.502	0.534	
Leg disablement	0.515	0.568	0.394	
Pain	0.316	0.250	0.413	
Limitation of movement	0.050	0.311	0.316	

The age-dependence of functional impairment and serology in RA is thus clearly illustrated. In all age-groups serology is best correlated with the indices of deformity and limitation of movement. Levels of significance are indicated conventionally

Table 35 shows correlation coefficients for the radiological stage of RA and measures on functional capacity The tendency towards a stronger correlation between disability measures and the radiological stage is also apparent here. For all ages, the strongest correlation is found for deformity and limitation, indicating that radiological grade for RA and positive serology are measures within the same sphere.

Quite a different pattern is found in the correlation matrix between disability measures and subjective disease troubles (Table 36). Here a

Table 38. *Stepwise multiple regression analysis*
Dependent variables

Age-group (yrs)	Steinbrocker functional class (Y_8)	Subjective assessment of disease troubles (Y_7)	Radiological stage (Y_8)
70–74	$Y = k - 0.12X + 0.33X_8 + 0.11X_4$	$Y = k - 0.26X + 0.32X_8 + 0.13X_4$	$Y = k + 0.72X_1 + 0.06X_4 + 0.01X_4$
	$Y = k + 0.39X_8 - 0.05X_1 - 0.05X_4$	$Y = k - 0.20X + 0.45X_4 - 0.13X_1$	$Y = k + 0.60X_1 + 0.02X_4 + 0.30X_6$
	$Y = -0.32 + 0.38X_8$ ** Arm-hand disablement	$Y = k + 0.14X_8 + 0.30X_4$	$Y = 0.05 + 0.61X_1 + 0.29X_4$
		$Y = 0.07 + 0.39X_4$ Pain	Deformity
56–60	$Y = k - 0.00X + 0.15X_8 + 0.22X_8$	$Y = k + 0.03X_1 + 0.36X_8 - 0.04X_8$	$Y = k + 0.53X + 0.14X_8 - 0.11X_6$
	$Y = k + 0.24X_8 + 0.01X_4 + 0.07X_8$	$Y = k + 0.28X_8 + 0.21X_1 - 0.06X_6$	$Y = k + 0.13X_1 - 0.07X_4 + 0.60X_6$
	$Y = 0.36 + 0.31X_4 + 0.34X_8 + 0.34X_8$ Leg-function disablement	$Y = 0.18 + 0.27X_8 + 0.21X_1$ Arm-hand disablement	$Y = 0.07 + 0.65X_8$ Limitation
42–46	$Y = k - 0.00X_1 + 0.26X_8$ $0.02X_8$	$Y = k + 0.09X_1 + 0.52X_8 + 0.14X_8$	$Y = k + 0.53X_8 + 0.31X_8 + 0.01X_4$
	$Y = k + 0.23X_8 + 0.04X_4 + 0.02X_1$	$X_1 = k + 0.29X_8 + 0.47X_4 - 0.01X_8$	$Y = k - 0.08X_1 + 0.14X_4 + 0.90X_8$
	$Y = -0.27 + 0.27X_8$ ** Arm-hand disablement	$Y = -0.0023 + 0.62X_4$ *** Pain	$Y = 0.25 + 0.92X_8$ Limitation
31–35	Calculations not meaningful	Y $k + 0.75X_1 - 0.11X_8 + 0.06X_8$	Y $k + 0.30X_4 + 0.34X_8 - 0.90X_6$
		$Y = k + 0.62X - 0.22X_4 + 0.22X_8$	$Y = k - 0.06X_4$ $0.33X_8$
		Y $-0.49 + 0.73X_1$ Deformity	Limitation

weak or no correlation is found for deformity and limitation but a strong correlation for arm–hand and leg disability and pain. This means that the patient has his own measure on the severity of his disease and that it often conflicts with the serological and radiological measures.

The correlation pattern for Steinbrocker functional class is of yet another type (Table 37). The highest correlation, which is not age-dependent, is found for arm–hand and leg disability but in age-groups 56–60 and 42–46 there is also a low-grade correlation for pain and limitation of movement.

Multiple regression analysis

Multiple regression analysis was made according to a method devised by Råde (1962) using Olivetti Programma 101. This desk calculator allows simultaneous regression calculation of three independent variables. As five were included, the analysis was performed in two or three steps. The purpose of this analysis was to establish which of the independent variables was contributing most to the correlation.

Stepwise multiple regression analysis:

- Dependent variables
  - Steinbrocker functional class (Y_6)
  - Subjective assessment of disease troubles (Y_7)
  - Radiological stage (Y_8)
- Independent variables
  - Deformity (X_1)
  - Arm–hand disablement (X_2)
  - Leg-function disablement (X_3)
  - Pain (X_4)
  - Limitation of movement (X_5)

Results of this stepwise multiple regression analysis are shown in Table 38. In age-group 31–35 results are very uncertain or not possible to calculate because of too small numbers and the influence of weighting. In the following discussion this age-group will not be considered.

In two out of three age-groups the strongest interrelationship exists between *Steinbrocker functional class* and grade of arm–hand disablement. In the third age-group the difference between the regression coefficients for leg and arm–hand disablement is virtually nil.

In two out of three age-groups, the strongest interrelationship exists between *grade of subjective disease troubles* and number of painful joints. In the third age group the difference between the regression coefficients for pain and arm–hand disablement is small.

In two out of three age-groups, the strongest interrelationship exists between the *radiological stage* and the number of deformities; the second strongest being between radiological progression and limitation.

These results were also valid when the weighting of certain individuals (p. 26) was considered, and, when using a big computer which allowed simultaneous handling of all five independent variables (age-group 56–60).

Some general conclusions might be drawn from Table 38. It seems obvious that the three clinical variables, Steinbrocker functional class, subjective assessment of disease troubles, and the radiological stage, although to some extent intercorrelated, measure three different features of disease. The RA person's assessment of his disease troubles differs in some degree from the purely medical evaluations represented by Steinbrocker's measure and the radiological stage of disease. This splitting up has probably several implications within areas in which the patients' decisions are but little medically influenced, such as gainful employment, income, and sick-leave. Many investigations reporting on the prognosis of RA obviously define "prognosis" from a purely medical viewpoint, not considering the patient's assessment of his arthritis.

Thus, all three variables are needed to arrive at a broad conception of disease.

Employment

General remarks

As regards long-standing disabling disease, its impact on employment is of prime interest in a sociomedical investigation. The general labour market situation varies not only between sectors of commercial and industrial life but also between areas, countries, level of industrialization, official and private opinions on handicapped, etc. In the case of RA, the female predominance gives rise to special problems connected with the participation of women in the labour force. Social security situation is also involved in general employment rate and absenteeism. The following brief description of the labour market will therefore primarily concern the situation of women.

Labour market mobility Womens employment

Labour turnover decreases with increasing age and training. In textile industry (Hedberg, 1967) only 10% of persons between 55 and 59 leave during one year as against 35% in the age-group 25–29 and this percentage increases in times of general prosperity The general principles of labour mobility are reviewed by Parnes (1954) and Hedberg (1967) in their surveys. In changing, giving up, or taking up gainful employment, it is difficult to distinguish between the individual's choice and the influence of the local or general labour market situation. The interdependence of these factors was studied by Hedberg (1967). In a detailed study of labour market mobility in a Swedish textile town (Rundblad, 1964), disease was not considered separately but 11–18% of the subjects reported unspecified reasons for change of work. It was, however remarkable that 7–40% of different groups could not specify the reason for their change of employment.

In his broad study of the Swedish labour market, Skogh (1963) also commented on the continuous increase of the female proportion of the labour force. According to the population and housing census 1965 the number of married economically active women increased during 1960–1965 by 140 000 to 534 000, but for men the corresponding figures were 12 000 to 2 290 000. This tendency is general and more pronounced in highly industrialized countries. Bauer (1968) summarized six factors contributing to this development, among them increasing urbanization, higher education, and earlier marriages. He also emphasized the decreasing degree of employment of the married woman with increasing income of her husband. The wide discrepancies between countries with respect to gainful employment of women, referring to 1960 were reported by Berglind (1968). The span was from 11% in the Netherlands to 38% in France. Even between the Nordic countries big differences are recorded. In 1960 only 10% of Norweigan married women were gainfully employed, as against 25% of Swedish women. The expansion of the women's sector of the labour market is especially noticeable in the highly expanding trade and economy of Japan, where the number of part-time employed women increased remarkably by 47% between 1966 and 1968 (Hedberg, 1969). Different classification problems produce difficulties in comparisons between countries and periods. In a large and comprehensive survey of women's employment in Great Britain (Hunt, 1968), nearly half the number of British married women were gainfully employed but only 1/5 were working full time. Womens occupational activities are twice as high in urban as in rural areas (Forsman, 1965).

In their extensive survey of women's work and life, Dahlström et al. (1962) found that the time given to household work was some 60% lower among gainfully employed women than among house-wives. The authors discussed the great overlapping of and difficulty in distinguishing between really necessary house-work and pleasant, but only sometimes useful, activities typical of

household work. The amateurish, rather traditional, character of household work, at which individual preference often weighs heavier than effectivity was also stressed. These points are definitely relevant to household activities of RA persons.

Women are still paid less than men for the same type of work, even though an equalization is proceeding (Inghe & Inghe, 1967). One argument for lower pay for women has been their higher absenteeism, which is reported by the vast majority of absenteeism investigators (Forssman, 1963 1965). When matched with males, by age, type of occupation, and salary women had similar absenteeism (Olsson, 1967). This might partly be the result of the labour-market development in a highly industrialized society Olsson also showed that increasing absenteeism was a feature of general economic prosperity in which institutional changes, such as increased sick benefits, played an insignificant part.

The labour market and the handicapped

In the interrelationship between the handicapped and labour market it is difficult to determine, whether the handicap or the labour-market situation is the main cause of non-employment. Medical literature in general concentrates on the handicap, its physical and psychological features, and does not consider the general labour-market situation. It is therefore very often impossible to compare results of different studies of employment and disability Often such studies unintentionally report more on labour-market situation than on the degree of successful employment of the handicapped person. Acetylsalicylic acid has the same somatic effects in Sweden as in Scotland, but the outcome of the employment status of patients is, to a great extent, the product of the society where the treatment is given. These viewpoints are also valid for the evaluation of rehabilitation projects.

Berglin (1959) in reviewing rehabilitation factors, mentioned the labour-market situation but *after* disease prevalence and age of population. Hanman (1951), in a survey of job placement of disabled persons, did not mention the labour market situation in numbering placement factors" Levenson & Green (1965) found that only 33% were gainfully re-employed of those who had received social security disability benefits and who suffered from diseases of the locomotive organs. In a large survey of handicapped in Denmark no differences were found in occupational profile between handicapped and non-handicapped persons (Andersen, 1966).

In Sweden the number of persons registered for vocational training increased more than twofold from 1962 to 86 184 in 1968 (Andersson & Morkvist, 1969).

From 1961 to 1967 the proportion of successful job placements from vocational training into the open labour market fell from 33.1% to 14.9% (Gogstad, 1969). The relatively unfavourable economic climate in 1967 is probably responsible for part of this decrease.

Imell (1964), in a series of bronchial-asthma patients, reported that 36% of the males, as against 11% of the females, had been forced to change employment because of their disease. Andersen (1964 *b*) found that 15% of male and 10% of female handicapped changed their employment because of disease. These two reports might mirror the generally greater mobility of the women in their connection with the labour market, as well as the heavier pressure on males to be gainfully employed. A survey of the present labour market policy and the handicapped in Sweden has been published by Olsson (1969), Director General of the National Labour Market Board. He stressed the difficulties in getting the handicapped accepted on the open labour market.

In a handicap situation, as in society in general, the sex roles are brought into the disease. Andersen (1964 *b*) recorded that handicapped males performed considerably less household work than did handicapped females. For instance, only 6% handicapped females did not do any household work, as against 52% of males. Lindstedt (1968), in a survey of 3 557 blind people in Sweden, found that 54% of the married men were to some extent gainfully employed, as against 5% of the married women.

RA and employment

General remarks

Besides the general labour market situation difficulties in comparison of employment rates are mainly found in three areas: (*a*) non-participation (*b*) selection, and (*c*) definitions of diseases. In many investigations into employment and RA at

least one of these factors interferes highly with the conclusions, as exemplified by the following three studies. In the large study by Ragan & Farrington (1962), comprising a long-term follow up of 500 clinical RA cases, only 176 were left for evaluation after ≥ 16 years. Of these 176 patients, only 32 % had no employment. The employment figures were fairly constant through different follow-up periods, with a concurrent considerable increase of the non-participation group. Ragan & Farrington also pointed out that an initially advanced stage of disease implied a higher risk of future non-participation.

The study by Manheimer et al. (1960) and Manheimer (1962) concerned a "back-to-work program for persons 16–65 years of age, unemployed and suffering from diverse disabling diseases. Out of 533 disabled patients, two-thirds had rheumatoid arthritis. A total of 41 % of these 533 were placed in competitive jobs in 1953 through 1961 However, to qualify for this project, the participant should be willing and able to go to the ambulatory rehabilitation centre. This selection factor probably contributed to the relatively favourable results of this often quoted study

The study by Lincoln & Cobb (1963) included 331 industrially employed men. They found that during a 28-month period 5 % fulfilled, at least once, the clinical criteria for definitive RA. The rate of absenteeism for this "RA group was said to be but little more than that for their joint healthy colleagues. This lack of difference between a RA and a non-RA group with respect to absence from work is probably to a fairly large extent due to the wide definition of RA used by Cobb.

Reports on RA and employment rate

In Table 39 *a* are listed some results from reports on RA and employment rate. The materials are naturally heterogeneous but, in virtually every report, some RA patients were working in spite of severe disability Thus, even in selected hospital materials, a not insignificant number of the patients were gainfully employed.

Employment and RA Degree of disability

Several investigators agree on the main conclusion that there is no direct correlation between employability and stage of disease (Margolies, 1959 Manheimer 1962, Carrol & Brull, 1966 Kim, 1969 Acker 1959 Steinbrocker 1969).

The reports that are mostly pessimistic with respect to employability of RA cases represent a minority of the literature in this field.

Pinner (1962) reported that only one of four patients with arthritis could be given employment through New York State Employment Service.

Robinson (1969) mentioned that ability to work is related largely to functional capacity and, to a lesser degree, age However the same author (Robinson, 1958) had found a positive result by rehabilitation of 21 RA patients, 15 of whom were re-employed. In Hollander's textbook on arthritis and allied conditions (1966) Lowman states that job placement of the disabled arthritic is still one of the most difficult problems Werne (1965), in surveying the rehabilitation problem, stressed the vital importance of the function of locomotive organs for gainful employment.

In another report, Duthie et al. (1955) found that the functional capacity of manual workers was higher than that of professional and clerical workers. This in conflict with the opinion of Dixon (1965). In reporting on 95 male and 21 female RA patients with employment difficulties, Partridge (1963) mentions that the unsatisfactory result of resettlement was partly due to the high rate of unemployment in the area.

Disability evaluation of housewives with RA

As was pointed out on p. 86 the individualized and flexible extent of household work renders it a difficult field for evaluating the impact of disease as well as the success of therapeutic measures.

This problem has been approached in different ways. The way of depersonalization was chosen by Moos & Solomon (1964 *b*). Not employed persons, as housewives, were by these authors classified according to the occupation of the person upon whom they were dependent for support Duthie et al. (1955) applied a special functional grading 1–4 for housewives, in which 1 meant that the housewife could manage all housework and 4 that she was incapable of any housework. The assessment of the effect of the disease on earning capacity was considered to be very difficult in a group consisting of many housewives.

Brooks (1969), in his cost-benefit analysis of

Table 39 *a. Some reports on RA and gainful employment*

Author	Year	Country	Material	Results
Kellgren et al.	1953	Great Britain	109 RA persons in population survey (Leigh)	50 % had lost no working hours during 5 years
Short et al.	1957	USA	Long-term follow-up of 293 hospital cases of RA	No differences between RA cases and general population with respect to gainful employment
Lowman	1958	USA	A 5-year follow-up of 38 RA patients, many severely incapacitated	4 out of 17 severely disabled and 8 out of 21 moderately disabled gainfully employed after rehabilitation
Clarke	1959	USA	32 home-bound arthritics	75 % able to do some industrial home work, earning 2–60 $/month
Goldman	1959	USA	"Back-to-work-project" of 331 arthritics	40 % of clients had become self-supporting
Duthie et al.	1960	Scotland	Follow-up of 112 RA hospital cases	Employment significantly affected by RA in 64 % of males, 85 % of females. Only 1 of 13 females employed at admission regained full-time work
Laine & Leminen	1960	Finland	115 hospital cases of RA 152 RA persons in 1958 registered with an employment agency	27 % incapable of all work Only 63 placed in gainful employment
Brown & Lingg	1961	USA	255 factory workers; 10 with RA	Average 10 sick-days/year for the RA cases
Munheimer	1962	USA	533 disabled persons in back-to-work program, 2/3 had RA	During 8 years 41 % placed in competitive jobs
Ragan & Farrington	1962	USA	Long-term follow-up of 300 hospital RA cases	32 % of 176 followed-up for >16 years had no employment
Beck	1963	USA	General review	"... extremely difficult to find criteria by which to differentiate the arthritic patient who is able to work from the one who cannot work"
Harris	1963	Great Britain	986 RA patients from rehabilitation clinic: some followed up after 2–3 years	48 % totally or partially settled or resettled
Partridge	1963	Scotland	Follow-up of 95 male and 21 female RA patients with employment difficulties	63 patients returned to work within one year of referral. Patient's attitude most important single factor
Levi	1964	Sweden	An 8-year follow-up of complex rehabilitation material of 125 persons; 4 had RA	Of RA patients 2 were not employable, 1 employable, and 1 at work
Laaksonen	1966	Finland	A 16-year follow-up of 544 cases of juvenile RA	Supporting themselves: Functional class 1 41 % 2 49 3 10 %
Gogstad	1968	Norway	Follow-up of 672 patients from rehabilitation institute	5 out of 29 persons (RA or spondylarthritis) were not gainfully employed
Taylor & Fairrie	1968	Great Britain	366 disabled refinery workers; 13 had RA	RA cases in all four disability grades
Berglund & Brattström	1969	Sweden	285 hospital cases of RA; 62 % in functional class III–IV	32 % of males and 9 % of females gainfully employed outside their homes

366 RA patients, 159 of whom were housewives, was forced to assume that as a rough approximation, the housewive s work had the value of domestic-help wages. In the study by Wijnmalen et al. (1960, 1966) of 185 Dutch housewives with RA, the extent of a housewife s work was established according to a not specified general opinion of this work. They concluded that it was not possible to measure the work volume of the house wife, so a relationship between actually performed work and functional capacity was assumed and applied. By that definition 54% had no or slight incapacity

Some statements focus the conventional view on the different rehabilitation goals and different employment rates for men and women.

Harris (1968) mentions that as men have less home responsibility they are more likely to attend regularly for exercise and also find it easier to keep to home exercise program This was also noted in a study of 109 elderly rehabilitation patients (Gray et al., 1964).

Harris (1963) stated that "It was difficult to make the [occupational] assessment in women, as the majority (75%) were housewives or did no paid work" However Harris was optimistic on the RA women's occupational resettlement. "There is no problem with job placement· the kitchen is ready waiting!"

Summary and conclusions

The general labour market situation is of impor tance to the employment of RA persons but is neglected in medical reports. Comparisons, as well as interpretations, of individual therapeutic results and of the impact of disease will thereby be difficult, especially as several investigators report weak correlations between functional capacity and employment rate. However many medical investigators seem to look upon the women with RA as a problem *not* with respect to gainful employment but only to household work. The development of the labour market in countries with a dif ferentiated industrial and commercial life makes this view less valid.

CHAPTER XXII

Gainful employment and RA syndrome. Data from the present survey

General economic climate during the investigation period

In the industrialized countries the world-wide recession over 1965–1967 was only partially mirrored by increased unemployment figures. Large groups of predominantly female labour were not registered as unemployed.

During 1965–1967 the demand for labour in Sweden decreased by nearly 50 %. In 1968 the official unemployment rate was the highest since 1958–1959 being 2.9 % in the first, 1.7 % in the second, 1.4 % in the third, and 1.9 % in the fourth quarter (Arbetsmarknadsstatistik no. 2, 1970, Table 39). These figures are roughly twice as high as the corresponding ones from 1965.

Out of 58 000 persons included in the labour market policy in 1967 41 900 were under re-education or vocational re-training (Ekonomiska utsikter våren 1968. Swedish Confederation of Trade Unions). Information on detailed medical diagnoses in these persons is lacking. In 1967 a follow-up investigation was made of 4 040 persons who, over the period April–May 1964 completed their official vocational resettlement training (Arbetsmarknadsstatistik no. 5 B, 1969). Among the physically disabled 90–95 % had been gainfully employed, half having had two jobs. Only 55 %, however, the same for both sexes, were employed without interruption.

The economically active proportion of the population in Stockholm City in 1965 was 53.1 % for married women *without* children living at home and 37.7 % for those with children. For not married females, these proportions were 66.2 % and 73.8 % respectively. In rural areas in Sweden, these proportions were 10–15 % lower (Population and Housing Census 1965. Part IV. Central Bureau of Statistics, Stockholm 1967.)

For the proportions of economically active in age-groups close to those in the present survey see Table 39 *b*.

Gainful employment. Questions and some definitions

From the foregoing presentation it is seen that several factors will contribute to a high rate of gainful employment among women in Stockholm. An analysis of the influence of epidemiologically defined RA on gainful employment would therefore be meaningful on the basis of the present study.

Questions relating to employment used in this part will be found in the first interview form (Appendix III, p. 129), items 2–8, and in the re-examination form (Appendix IV. p. 131) items 24–28. At re-examination, these as well as other answers were up-dated. Generally speaking, only small changes occurred from the first to the second interview. If not placed in sub-categories of item 2, the respondent was asked specifically about his profession. This was later coded with three figures according to occupational classification used in the population and housing census 1961, also described in the Nordic Occupational Classification 1962. Two main measures on gainful employment were used.

The answer to the first question on occupational classification (What is your present main employment or occupation?) placed the respondent in the answer to the second question (Did you do any wage-earning work last week (last seven days)?) on working-hours, the seven days preceding the interview were used as reference period. This question will therefore not refer to the same period for all individuals but, on the other hand, the answers will be fairly accurate. As interviews were not made close to major holidays, these data could be considered to be rather stable. Seasonal variations are small (Olsson, 1967). Part-time work was defined as all work less than 40 hours and fulltime work as 40 hours or more a week.

Table 39 *b* *Percentage of economically active persons in 1965 in Stockholm City by sex, age and civil status (Population and Housing Census, 1965)*

Age-group yrs. –	30–34	35–44	55–64
Men	*83*	*[illegible]*	*87*
Women			
Married	*37*	*49*	*38*
Not married	*93*	*93*	*68*

Table 41 *Percentage of gainfully employed by civil status (C = contrast)*

	Males Age-group, yrs.				Females Age-group, yrs.			
	56–60		42–46 31 35		56–60		42–46 31–35	
	RA	C	RA	C	RA	C	RA	C
Married	*78*	*100*	*90*	*100*	*33*	*48*	*68*	*52*
Not married	*89*	*100*	*100*	*100*	*80*	*75*	*93*	*100*

Employment in pensioners group

As the age-group 70–74 represents largely economically inactive individuals, it was not included into the analysis of employment data. However in the contrast age-group 70–74, 13 out of 84 had some gainful employment. In the same RA age-group, 3 of the 64 were similarly employed.

Among those 29 drawing a disability pension for RA in age-range 31–60, 2 had some gainful employment. In the whole RA group 5 pensioners had some work; 3 of them had radiological grade four for RA.

Disability pension

A total of 46 persons out of 293 drew or had drawn disability pensions. In age-group 70–74 those who received such pension before the age of 67 were included. In Table 4 are shown numbers and proportions of pensioners in different numbers of RA criteria (1966) and age-groups. With increasing number of criteria the proportion of disability pensioners increases. However even of those classical" cases fulfilling three or four criteria, approximately only 1 out of 4 drew a disability pension. The proportion of disability pensioners increased fourfold with increasing age. The rise should have been even higher if the non-participants in re-examination had been included. There is no significant sex difference between the proportions of disabled pensioners.

For 143 persons in age-group 56–60 the incidence of disability pension during 1959–1966 averaged 1 6 persons per year

In conclusion, 1 out of 4 persons fulfilling three of four RA criteria (1966) is likely to re-

Table 40. *Education and employment RA and contrast groups 56–60 42–46 and 31–35 years. Percentage of total in each group* (C – contrast)
Weighted numbers

	Males Age-group, yrs.						Females		Age-group, yrs.			
	56–60		42–46 31 35		Total		Total		56–60		42–46 31 35	
	RA	C	RA	C	RA	C	RA	C	RA	C	RA	C
Numbers –	32	44	18	78	50	122	179	250	111	104	68	146
Only elementary school	*88*	*68*	*89*	*60*	*88*	*63*	*75*	*61*	*78*	*74*	*69*	*52*
Junior high school or equal education	*9*	*11*	*5.5*	*17*	*8*	*15*	*23*	*30*	*19*	*21*	*31*	*37*
Higher secondary school or university	*3*	*21*	*5.5*	*23*	*4*	*22*	*1.7*	*9*	*3*	*5*	*0*	*11*
Vocational training and gainfully employed Yes	*28*	*39*	*61*	*64*	*40*	*35*	*34*	*32*	*23*	*27*	*50*	*35*
Vocational training and gainfully employed No	*0*	*0*	*0*	*0*	*0*	*0*	*15*	*15*	*15*	*13*	*15*	*16*
Change of employment because of disease	*22*	*9*	*31*	*1.3*	*26*	*4*	*7*	*3*	*7*	*5*	*7*	*1.3*
Gainful employment for more than 5 years in present occupation	*75*	*80*	*83*	*90*	*78*	*86*	*49*	*49*	*53*	*51*	*43*	*47*
Gainful employment	*81*	*100*	*94*	*100*	*86*	*100*	*63*	*62*	*37*	*57*	*76*	*64*

Table 42. *Disability pension vs. criteria for RA and age*

	Males			Females			% of total M+F
	Yes	No	% of total	Yes	No	% of total	
Criteria for RA 1946							
1	1	11	*8*	1	42	*2*	*4*
2	2	14	*13*	8	92	*8*	*9*
3	6	11	*35*	15	41	*27*	*28*
4	3	9	*25*	10	27	*27*	*27*
Age-group (yrs)							
70–74	5	2	*71*	12	45	*21*	*27*
56–60 42–46	5	27	*16*	18	93	*16*	*16*
31–35	2	16	*11*	4	64	*6*	*7*
Total	12	45	*21*	34	202	*14*	*16*

ceive a disability pension. This likelihood increases fourfold with age, and might be higher for males.

Education, employment rate, and change of work because of disease

Some basic data concerning education, employment rate, and change of work because of disease are found in Table 40 for RA and the contrast group. One striking feature is the significantly ($p<0.01$) lower proportion of RA males and females with higher secondary school or university in comparison with the contrast group. This is, however in accordance with the observations by Engel et al. (1966) and Adler & Abramson (1968) and is also valid for a general restriction in moving about (Hilsa-Yrke-Bostad, 1964). Similar findings were indicated by Rimón (1969) in his study of 100 hospital female RA patients, of whom 66 were gainfully employed. RA is probably here only one part of the general higher morbidity in lower social class.

All RA and contrast men with vocational training were gainfully employed. Among females, roughly 3 out of 4 with vocational training were gainfully employed and this does not differ from the data in the contrast group. As many as 26% of RA males, as against 7% of RA females, had changed work because of their disease. This difference is highly significant ($p<0.001$). In general, there were no differences in the overall percentage of gainfully employed between the RA and the contrast females but RA males were significally less ($p<0.001$) gainfully employed than were contrast men. Duration of disease did not influence significantly the proportion of gainfully employed.

One conclusion is that men change work because of RA significantly more than do women. However a vast majority of those gainfully employed had had their present work for more than five years. Thus, RA women tend to leave the labour market but RA men stay or change employment. In the whole RA group 18 out of 28 persons who changed work because of joint disease had radiological grade 2 or lower

The influence of civil status on employment rate was virtually the same in the RA and the contrast group, as will be seen in Table 41 The higher employment rate for married RA women in comparison with married contrast women is, however not statistically significant.

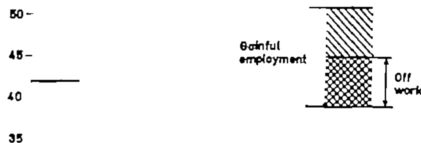
Occupational grouping

By using the classification of major occupational groups found in Nordisk Yrkesklassificering (1962) (Nordic Classification of Occupations) it became possible to study the crude distribution of occupational classes in RA and contrast groups. No attempt was made to find relationships between a certain occupation and the prevalence of RA. As the enormous variety of occupations expose the individuals to different kinds and degrees of strain, damp, etc., meaningful correlations with the difficultly delineated RA syndrome are not possible in the present survey

However a classification according to major occupational group might indicate differences in

Table 43. *Distribution of occupational branches RA and contrast groups based on unweighted numbers on age-groups 56–60 42–46 and 31–35*

Group	Sex	Total	Groups of occupational branches: 0	%	1 2	%	3–8	%	9	%
Contrast	M	122	31	*25*	19	*16*	69	*57*	3	*2*
	F	155	24	*15*	55	*36*	39	*25*	37	*24*
RA	M	33	3	*9*	5	*15*	22	*67*	3	*9*
	F	77	8	*10*	19	*25*	34	*44*	16	*21*





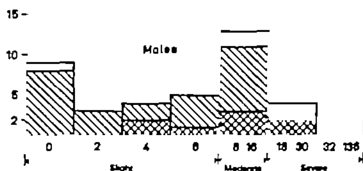


Fig 29 Gainful employment and grade of arm-hand disability. Age-group 56–60, 42–46, 31 35. Unweighted numbers.

occupational profile between the RA and the contrast group. Table 43 shows such a classification using the offical major occupational grouping. 0" is equivalent to qualified work mostly of academic nature (e.g. engineers, teachers), 1–2" includes administrative and office work, 3–8" commercial, transport, and manufacture work, and "9" service occupations. RA men are represented in an indicatively lower proportion ($p<0\ 1$) in the qualified occupational group "0" compared with contrast men. In the contrast group the distribution of occupational groups between sexes were significantly different ($p<0.05$). In the RA group the differences were similar but

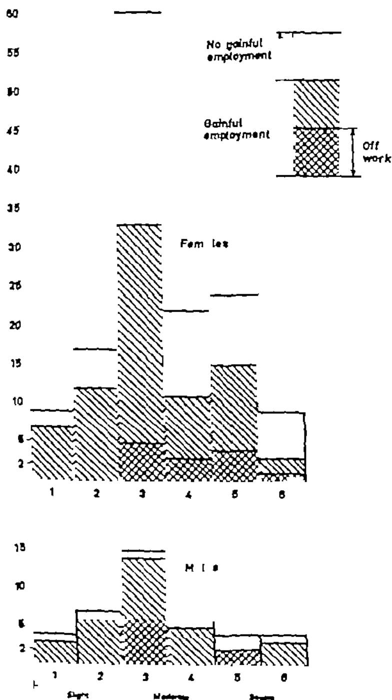


Fig. 30. Gainful employment and grade of subjective disease troubles. Age-group 56–60, 43–46, 31–35. Unweighted numbers.

not statistically significant, except for occupational groups 3–8 ($p < 0.05$).

In conclusion, RA persons are underrepresented ($p < 0.05$) in more qualified occupations which reflects, partly or largely the lack of higher education found in the RA group.

Disability grade and gainful employment

Two separate measures, namely arm–hand disability and subjective assessment of disease troubles, were used to illustrate the decrease in employment rate with increasing disability. Figs. 29 and 30 show the numbers of gainfully employed, of those temporarily off work, and of those who were not gainfully employed. To reduce the effect on estimations, those represented by weighted numbers and generally with few signs of disease are here represented by unweighted figures. A finer grading of disability than that found on p. 82 was used here.

In Fig. 29 gainfully employed are found in each grade of disability with the exception of the males with the most severe arm–hand disablement, which might mean, for instance, at least four functions performed with great difficulty. Ten of them were gainfully employed but 4 of these 10 were temporarily off work.

An off work group, however also exists in lower grades of disability. The patient's own measure, subjective disease assessment, is used in Fig. 30. It will be seen that out of the total of 41 with severe subjective disease troubles, 23 were gainfully employed byt 7 of these were temporarily off work. These two measures give separate profiles for disability and employment rate.

No differences with respect to site of subjective main disability were found between proportions of those who were and those who were not gainfully employed. This site was reported to be the hands in 37% and 29% respectively. Similar results were found for the knees.

Employment and severe disability

It will be seen from Fig. 29 that 6 women, all in age-group 56–60, with severely impaired arm-hand function were gainfully employed and at work the week before the interview. Two were cleaners, two shop assistants, one was a telephone operator and one a cashier.

A comprehensive presentation of data on one of the cleaners will make her situation concrete.

Record no. 1570 A 60-year-old married woman, no. 2 of seven children. Had worked as a cleaner for more than 10 years. Worked 10–20 hours pre-interview week. RA for 14 years. Multiple severe erosions, up to grade 5 both in hands and feet. Negative SSCT and AFT. Painful swollen ankles and MCP joints. Bilateral ulnar deviation, swan-neck deformity bilateral painful limitation of shoulder movement. No physical therapy for one year. She considers that her joint disease causes only moderate troubles. She finds her medical care sufficient. Accepted six new ADL devices. Hospitalized four times since 1954. Also suffering from bronchial asthma and hypertension (220/130 mmHg), but does not mention them spontaneously. Feels nervous and tired. Lives in a modern two-room flat. Taxable income for 1965, 9 690 Sw. kronor, husband' 21 660. In 1955–1966 sick-listed for 683 days for RA. Unable to open water tap without ADL device, and eight other arm–hand functions moderately impaired. Can enter bus with great difficulty.

Gainful employment and number of criteria

From some viewpoints, the relation between gainful employment and number of criteria for RA (1966) represents the influence of medical variables on economic activity. This is illustrated in Fig. 31 together with comparable data from the contrast group. Weighted numbers were used. The economic activity of the RA men is considerably (13–25%) and significantly ($p < 0.01$ $p < 0.001$) lower than that of the contrast men, for two to four criteria and decreases, but not significantly so with increasing number of criteria. For RA women, the occupational activity is not significantly lower than that of the contrast women up to four RA criteria, when it drops sharply and significantly ($p < 0.05$). This is in agreement with the finding (Table 40 p. 92) that RA females do not change work but quit instead.

The general conclusion might be drawn that RA women preserve an employment rate similar to that of the contrast women, with the exception of those fulfilling four criteria, who show a significantly lower ($p < 0.05$) labour force participation. RA men are at virtually all levels less gainfully occupied than the contrast men and their occupational levels are but little influenced by the number of criteria. Thus, RA men, unlike RA women, deviate from the general sex-linked occupational activity.

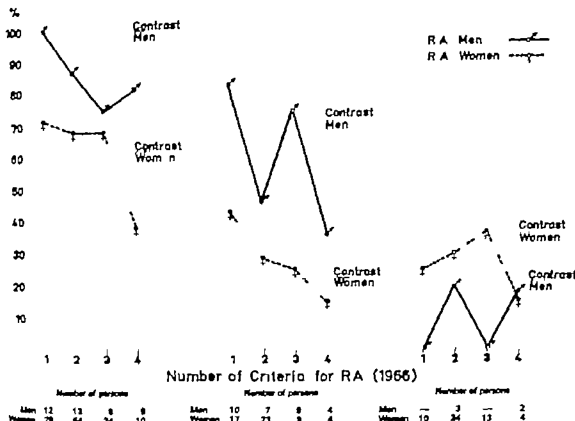


Fig. 31 Percentage of gainfully employed based on total number of persons fulfilling different numbers of criteria for RA (1966). Age-group 56–60, 42–46, and 31–35. Mean proportions in contrast groups are given as reference.

Gainful employment and eight indices on disability and disease progression

Some interrelationships have been shown between different disability measures and grades of disease progression. The eight indices presented on p. 82, divided into (a) no or slight, (*b*) moderate, and (*c*) severe disability were used to illustrate their influence on the proportion of gainfully employed (Fig. 32) and on those gainfully employed but not at work in the pre-interview week (Fig. 33). Unweighted numbers were used to reduce the effect of those with slight signs and symptoms of disease. Some main conclusions can be drawn from the figures:

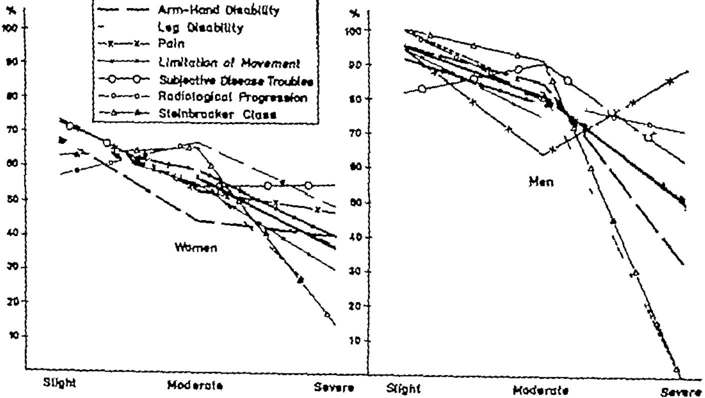
(a) In both sexes the average proportion of gainfully employed (Fig. 32) is decreased—from slight to severe grade of disability—by half being 66.8–36.7% for females and 94.6–50.4% for males.

(*b*) For separate indices (Fig. 32) no statistically significant differences in proportions of gainfully employed were found between the sexes in the highest disability grade. Figures are, however small.

(*c*) In the lowest disability grade (Fig. 32) females were statistically *less* gainfully employed than men with respect to arm–hand disability ($p < 0.05$) and leg disability ($p < 0.01$).

(*d*) In the grade of *moderate* disability (Fig. 32) females were statistically *less* gainfully employed than men with respect to arm–hand disability ($p < 0.05$), Steinbrocker class 3 to 4 ($p < 0.01$), and subjective disease troubles ($p < 0.01$).

(*e*) The average proportion of those temporarily off work (Fig. 33) is—with rising grade of



Women

DISABILITY

Number of persons

DISABILITY INDEX

		1	2	3	4	5	6	7	8
Slight	Tot	48	87	88	45	78	8	78	83
	Obs.	33	58	57	33	51	5	18	36
Moderate	Tot	63	34	38	61	42	112	62	38
	Obs	37	15	20	27	23	73	44	28
Severe	Tot	30	20	21	46	23	21	33	38
	Obs	12	8	4	21	7	3	18	19

Men

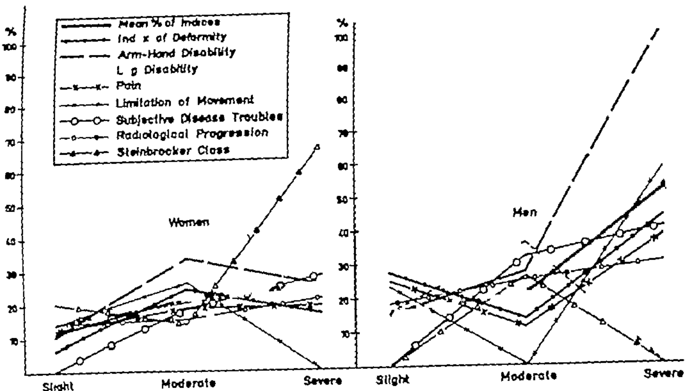
DISABILITY

Number of persons

DISABILITY INDEX

		1	2	3	4	5	6	7	8
Slight	Tot.	12	21	19	17	18	2	11	11
	Obs.	11	20	18	16	17	2	8	11
Moderate	Tot.	19	12	17	14	12	34	21	18
	Obs	16	11	14	9	9	31	18	12
Severe	Tot.	9	6	4	8	10	4	8	14
	Obs	7	2	0	6	7	0	8	10

Fig. 32. Proportion of gainfully employed of total numbers eight measures on RA disability and disease pro-



DISABILITY

Number of persons
DISABILITY INDEX

		1	2	3	4	5	6	7	8
Slight	Tot	32	69	67	33	61	8	19	39
	Obs	2	8	8	4	7	1	0	5
Moderate	Tot	37	15	20	27	23	73	44	26
	Obs	8	6	4	6	8	10	8	4
Severe	Tot	12	8	4	21	7	3	18	19
	Obs	2	2	1	4	0	2	5	4

DISABILITY

Number of persons
DISABILITY INDEX

		1	2	3	4	5	6	7	8
Slight	Tot.	11	20	19	16	17	2	8	11
	Obs	3	3	3	4	4	0	0	2
Moderate	Tot	16	11	14	9	9	31	19	12
	Obs.	2	3	5	1	0	5	8	3
Severe	Tot.	7	2	0	8	7	0	5	10
	Obs	3	2	0	3	4	0	2	3

Fig 33 Percentage off work in interview work of gainfully employed; eight measures on RA disability and disease progression.

disability—increased twofold for females and threefold for men, being 11.2–25.2% for females and 15.5–51.2% for males. Numbers are generally small and no statistical differences in separate disability measures could be established between sexes within the same disability grade.

(*f*) For *females* the proportion of gainfully employed (Fig. 32) was statistically significantly lower for arm-hand disability and subjective disease troubles ($p < 0.05$) in the low than in the moderate disability group. The differences between proportions of gainfully employed in the slightly and severely disabled group were significant ($p < 0.05$ $p < 0.001$) for all indices *except* for subjective disease troubles and radiological progression. These two variables, therefore, do not seem to be useful in distinguishing off-work groups from working groups.

(*g*) For *males* the differences between the proportion of gainfully employed (Fig. 32) in the "slight disability" and the "severe disability" group were significant only for arm-hand and leg disability ($p < 0.01$ and < 0.001 respectively). No statistically significant differences could be established between the "slight" and the "moderate" disability group.

(*h*) No statistically significant differences (Fig. 33) in disability measures could be established between proportions of temporarily off work within the same sex.

Conclusions

Generally speaking, the average *severely* disabled RA man was gainfully employed to the same extent as the average *moderately* disabled RA woman. Considering the off-work group, there were no sex differences within the "low" and "moderate" disability groups but there was a tendency to higher absence from work for men than for women in the severe disability group.

Income

General remarks

Several investigations, e.g. Burnight (1965), have shown the close relationship between high morbidity and low income. The general views on disease and economy are the same as those found on p. 86 in the discussion of the labour market. Country area, industrialization, and employment rate must be borne in mind, as must sex and *social insurance system, when the assets of sick* persons are considered. In Stockholm in 1965 48.4 % of females had an income below 10 000 kronor as against 18.1 % of males (Statistical Year Book of Stockholm 1966). For the whole of Sweden, in 1964 the corresponding figures were for women 67.8 % and for men 26.4 % (Statistical Abstract of Sweden 1966) implying higher incomes in the capital of the country. General problems on the distribution of income in Sweden and defects of income information are discussed by Bentzel (1952).

Previous investigations

In the US in 1962–1963 (Vital and Health Statistics 1964) it was found that the proportion of those reporting arthritis and rheumatism rose sharply from 8.7 % to 59.3 % from the income class of > $7 000 to that of < $2 000. This *general tendency was independent of age.* For RA, Engel et al. (1966) found twice as much RA as expected in income classes below $2 000.

Duthie (1967), in a report on 200 RA patients, stated that about 60 % were able to regain social and economic independence.

Duthie et al. (1960) found little detailed information available "as to the effect of rheumatoid arthritis on social and economic status of the individual" They reported, however that out of 112 RA patients, 29 had experienced considerable economic distress because of disease. The same was found by Laine & Lemunen (1960) who mentioned that 33 % of their RA patients had "very poor economic status".

In the Danish study of handicapped (Mogensen, 1967 and Andersen, 1964 *b*) it was reported that the average income of handicapped in Copenhagen was about [illegible]0 % lower than that of the total population of that city No special study was made of those 149 subjects with RA and OA.

For 42 cases of bronchial asthma, John & Wilhelmsen (1967) found that the median income of those with an income was 11 692 kronor as against 14 208 kronor for the whole sample of 1988 investigated persons.

A few reports consider the economic status of a diseased group through a period of years. Levi (1964) reported on incomes of severely handicapped persons in 1957 through 1961 He found a considerable increase of incomes after rehabilitation. Posner & Houser (1969), standardizing for family size, presented an analysis of the income development in 84 families, each with a case of multiple sclerosis. In 62 families no change of income occurred over one year in 16, the incomes increased and in 6 they decreased.

In conclusion, detailed reports on the economic status of RA or other handicapped persons are rare in the medical literature. However the increasing interest in, e.g., cost-benefit analysis and public health might stimulate research in this field.

Present study

General considerations

Sources of information on income are dealt with in Appendix IX, p. 137 As a general approximation, the "real" income would be 20–25 % higher than the taxable income. The object of this part of the survey was to study the development of incomes through a period of 11 years, using information from 1955 1960, and 1965 As income varies considerably with civil status, family size, and occupational stability age-group 56–60 would best serve as the basis for such an analysis. For 143 RA persons in age-group 56–60 years, 23 changes in civil status were recorded be-



Fig. 34 Mean taxable incomes in 1955, 1960, and 1965 for RA and contrast groups, (age-group 56–60). Individuals and spouses.

tween 1955 1960, 1965 and the time of interview For the 148 corresponding contrasts, 22 changes were recorded. It will be seen from Table 40 p. 92 that occupational stability was high both for the RA and the contrast group. Another prerequisite for the analysis was that the influence on taxable income of small children was similar and low both in the RA and the contrast group. The age of children was not collected. However there was no significant statistical difference in the number of children between the RA and the contrast group. According to Statistical Year Book of Stockholm (1967), 5.3% of gainfully employed married women 55–64 years old had children under 16 for the 45–54 age-group the corresponding figure was 31%. In the following analysis unweighted numbers are used.

For contrasts, information is lacking on one of 444 incomes for RA persons, four out of 357 incomes were not obtained. Similar losses of income information were recorded for spouses. In the following taxable income is referred to as "income if not otherwise stated.

Income development 1955–1965

Fig. 34 shows the mean taxable incomes in age-group 56–60 for 1955 1960 and 1965 for both sexes and for RA and contrast groups, also considering the spouse. For mean values in the RA and contrast groups, 95% confidence limits of the mean are shown. Even if the general tendency to higher incomes in the contrast group is obvious and confirmed by the uniformity of the incomes of spouses, strictly *statistically* significantly higher mean incomes are found only for mean incomes of contrast men in 1965 This is, however in concordance with the findings in the chapter XXII on *gainful employment (p. 91).*

The mean increase per year of mean income was 2.9% for RA males, as against 10.5% for RA females. For the contrast men, the corresponding figure was 7.5% and for the contrast women 5.7% The higher figure for RA females might, to some extent, mirror the increasing participation of females in the labour market together with rising wages for females.

Table 44 *Changes of taxable income class 1955–1965 Incomplete income sequences not included*
Age-group 56–60 yrs.

Group	Grade of arm-hand disablement	Change of income class	Period 1955–1960 M	F	1955–1965 M	F	Total no. of changes M	F	Median income (Sw kronor) 1955 M	F	1965 M	F
	No or slight (0–6)	Higher	3	22	5	31	8	53				
		Same	6	20	6	11	12	31	8 600	3 700	12 800	7 900
		Lower	4	7	2	7	6	14				
RA	Moderate (8–16)	Higher	3	10	4	11	7	21				
		Same	2	14	0	12	2	26	9 900	1 800	15 900	4 700
		Lower	1	3	2	4	3	7				
	Severe (18–136)	Higher	1	11	1	14	2	25				
		Same	3	6	2	3	5	9	8 400	0	5 200	7 200
		Lower	1	0	2	0	3	0				
Total RA		Higher	7	43	10	56	17	99				
		Same	11	40	8	26	19	66	9 000	3 600	12 800	7 200
		Lower	6	10	6	11	12	21				
Contrast		Higher	24	37	39	61	63	98				
		Same	18	55	3	25	21	80	12 100	3 700	23 000	7 700
		Lower	2	11	2	17	4	28				

It is clear that *sick benefits influence this estimation of incomes*, because sick benefits are free of income tax. Individual calculations were therefore made for RA and contrasts, assuming that one-third of the sick days in every four year period occurred in the income year Taxable income was transformed into real" income (see Appendix IX, p. 137). The increase on Jan. 1 1963 of the sick benefits through the national sick insurance service was taken into calculation.

Thus including sick benefits, the mean incomes increased for RA men by 10–13% for contrast men by 4–5% for RA women by 12–17% and for contrast women by 5–8% implying a mean gain for RA persons of maximally 9%

The income gap between the RA and the contrast group is thereby somewhat diminished. It must be emphasized that the total economic situation for RA and contrast groups was not evaluated. The higher expenses for drugs, doctors, and transportation in the RA group were not taken into account. The RA group considered itself significantly ($p < 0.001$) more sensitive to the size of doctors fees than did the contrast group. To some extent, this held true irrespective of family incomes (Allander, 1970).

Changes of income. Grade f arm–hand disablement

The mean incomes indicate a somewhat, but not statistically significantly lower income for RA persons. *An analysis was therefore made with respect* to mean income and changes of income class. Income classes used were 0–199 200–*2 999 3 000–4 999 5 000–9 999 10 000–14 999* 15 000–19 999 20 000–29 999 and ≥30 000 kronor A finer grading of lower incomes was necessary in view of the general income structure of women (Skattetaxeringar samt fördelning av inkomst och förmögenhet, Taxeringsåret 1966).

Changes from one income class to another were recorded for the RA and the contrast group 56–60 years old, taking the 1955 income as the basis. Grade of arm-hand disablement was also included, being divided into slight" "moderate and severe Income-class changes thus calculated will be seen in Table 44 together with *median incomes for 1955* and 1965 For men, income changes of the same pattern appeared through all three disability grades. However the median income increased from 8 600 kronor in 1955 to 12 800 kronor in 1965 in the slightly disabled group. A similar increase was also noted for the moderately disabled men. However severely disabled men had a median-income *decrease* from 8 400 to 5 200 kronor. The contrast men increased their median income from 12 100 to 23 000 kronor For the RA men, 1 out of 29 income-class changes meant a lowering, as against only 21 out of 120 for the RA women.

For women, RA as well as contrasts, increasing median incomes were recorded from 1955 to

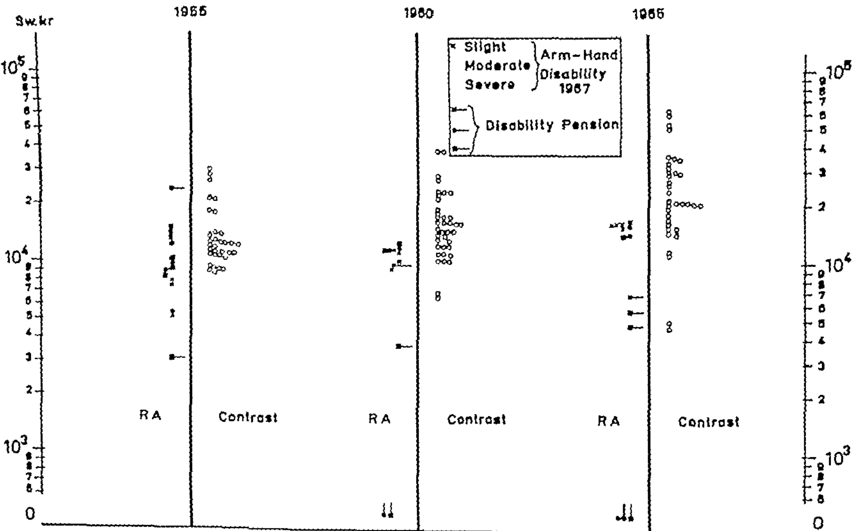


Fig. 33 Individual taxable incomes in 1955, 1960, and 1965 for RA and contrast men' age-group 56-60; grade of arm-hand disability in 1967

1965 *irrespective* of grade of disability. In fact, the highest increase was recorded in the severely disabled group. The moderately disabled group had the lowest median income in 1965.

The general conclusion can be drawn that RA men are economically relatively harder hit by disease than are RA women. Approximately every *second* income change for RA men meant a decrease, as against every *sixth* for RA women.

Individual incomes for men

The final part of the income analysis concerned individual incomes of the RA and the contrast group by sex. Arm–hand disablement was included, using the definition "slight" "moderate" and "severe" (p. 82). This is for men illustrated in Fig. 35. An important fact is that all high incomes, excepting one, are found in the contrast group. The difficulty to draw conclusions from this individualized material is, as a matter of fact, in itself a conclusion that we are concerned with a complex reality of which somatic disability is only a part. Only two persons, one severely disabled, both granted disability pensions between 1959–1962, had no incomes in 1960 *and* 1965. Many different combinations are found such as moderately disabled with relatively high incomes, slightly disabled with low incomes, etc.

Two cases illustrate the situation.

Record number 2614. Managing director, 60+ working full time, married, six children, large modern flat. Taxable income in 1965 was 78 750 kr. Wife without taxable income in 1965. Few erosions, grade 1 2, in hands and feet. Psoriasis. 263 days of sick-leave in 1955–1966. Joint symptoms for 5–10 years. No medical treatment. Operated upon for kidney stones three times and for gallstones in 1958–1962.

No functional impairment. Visited several doctors regularly. Considered his joint symptoms to be insignificant.

Record number 1378. 60-year-old married man, no children, modern 3-room flat. Taxable income in 1965 was 20 930 kr. Multiple severe grade of erosions in MCP of hands and multiple erosive changes at other sites in hands and feet. SSCT 1/80, AFT 1/320. Ulnar deviation, flexion contractures in hands, dislocation of MTP heads, painful shoulders with limitation of movement. No regular medication. No regular doctor's visits. No physical therapy in pre-interview year. Rheumatological surgery of feet and one hand 1 year before interview. Earlier pottery worker. Moderate alcoholic since 1936. Working in kiosk full-time at interview. His work arranged through the social authorities. Considered his joint symptoms causing very great trouble. Only five functions moderately impaired, obviously optimistic about his functional capacity which, in fact was relatively good. Sick-listed for 765 days over 1955–1966.

These two cases illustrate two extremes of disease, income, and employment as well as the difficulties in assessing functional capacity.

Individual incomes for women

Fig. 36 shows individual taxable incomes for females, in age-group 56–60 in 1955, 1960 and 1965. The clear-cut differences between the male RA and the contrast group are here absent. The number of disability pensioners increased from 8 in 1955–1958 to 13 in 1959–1962, and to 19 in 1963–1966. In the latter group of 19 persons, the incomes in 1965 were zero for only two, for the others between 4 800 and 9 000 kronor.

As for men, all combinations of disability and income are found. There is a substantial reduction of the group without income, in the RA group from 38 to 22 persons over the observation period, and in the contrast groups from 27 to 19. This is probably attributable both to pensions, which are taxable incomes and, in a less degree, to an increasing number of gainfully employed over the period 1955–1965. The general impression that for women the RA syndrome, irrespective of grade, has no considerable influence on economy seems reasonable.

The two severely disabled women with incomes of 21 500 and 15 300 kronor respectively both had painful limitations of movements in several joints of hands, feet, and shoulders together with joint swellings. None had positive serology or X-ray findings characteristic of RA. Both had moderate impairment of several functions, and had suffered from joint symptoms for more than 10 years. Over 1955–1966 they had been sick-listed for 532 and 1 735 days, respectively.

General conclusions

Income figures for a group are only partly equivalent to its total economic assets. The taxable income—some 20–25% lower than "real" income— used as uniform measure and applied to a socially stable middle-aged group for three years (1955, 1960, and 1965), was lower for both RA men and RA women than for contrasts. The difference was statistically significant only between RA and contrast men and only for 1965.

The inclusion of sick benefits decre

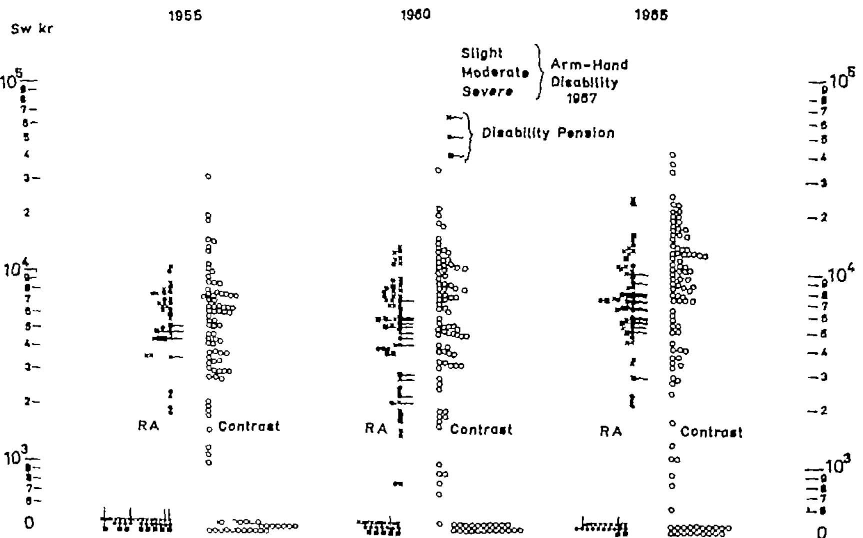


Fig. 36 Individual taxable incomes in 1955, 1960, and 1965 for RA and contrast women; age-group 56–60; grade of arm-hand disability in 1967

between RA and contrasts by maximally 9 %. The number of individual income-class changes during the observation period was noteworthy. RA men experienced a lowering of income three times as often as did the RA women, whose income patterns were similar to those of contrast women. Individual incomes for RA women were but little influenced by grade of disability. RA men were absent in higher income-classes and their incomes were probably somewhat influenced by grade of disability. The wide individual range of income, gainful employment, and disability was illustrated by three case histories.

Sick leave

Previous investigations

Besides selection, there are four main obstacles to adequate and substantial comparisons with respect to sick-leave data on RA.

(*a*) Insufficient or outdated definitions of the disease

(*b*) Clustering of diagnoses within the rheumatoid sphere into large groups in which the part comprising RA is difficult to assess,

(*c*) Wide range of official and individual sick benefits between countries and periods

(*d*) Different definitions of disability and of reduced working ability due to rheumatic disease.

As far as official statistics are concerned, these obstacles are nearly always present. Foreign investigations into sick leave for RA are of peripheral interest in the present study and are therefore only briefly reviewed. For current data from Sweden, the reader is referred to chapter I. Helander (1965) made a statistical survey in a county of Sweden comprising those who had been sick for > 90 days with the same disease. He found 140 such female and 69 male RA cases, which averaged 0.1 % of the total adult population in the county The mean number of total sick days for all long-term cases was 434 days. Jonsson (1964) reviewed some present and past information on rheumatism in Sweden but was sceptical about the results of epidemiological surveys. Recently morbidity and mortality data from Great Britain have been published (Digest of Morbidity and Mortality Data on the Rheumatic Diseases, 1969) For arthritis (ICD nos. 720–725) the average duration of spells of sick benefit was 96.6 days.

Extent, distribution, and turnover

To measure sick leave, the period 1955 through 1966, split up into three equal parts, was used. Details are found in Appendix IX, p. 137 An analysis was made using the total number of sick days for each period, adding days for RA and non-RA disease, thus giving the picture of officially recorded sickness. Table 45 shows percentage distribution of sick-leave days in R. and contrast groups together with the number of sick days among sick-listed. In Tı 45 and 46 mean and median numbers of sick do not include sick days for persons *after* havi been granted their disability pensions. Such si days refer only to hospital care and should logic ally be excluded from calculations, because qu a different probability for disability pensioners be sick-listed. For the 23 disability pensioners i age-group 56–60 the total mean number of si days before disability pension was 685 (range 1 469) days. *After* disability pension, a mean o 126 (range 0–602) was found for 16 persons, whom 14 had 180 sick days or less. The centration of sick days to > 90 days within ev. period in the RA group is apparent, being be tween 46 % and 79 % For the contrast group corresponding figures are 14 % and 27 % Ho ever 0 % to 28 % of the RA group had no si days. Of those altogether 87 *occasions* in the A group with no sick days during the three period under study only 32 represented persons dra a disability pension. The mean number of s days among those sick-listed is twice to times higher in the RA group the differences means between RA males and RA females are no significant.

Using the official special figures for RA, e if not totally comparable with those of the survey (ref no. 8, Chapter I on official statistics) an estimate can be made of the difference betweer mean number of sick days for the population survey diagnosis of RA and that for the purely medical diagnosis of RA. In the official study of 1966 referred to above, the mean number of sick days for RA in age-group 55–59 years was 133 (23 cases) for males and 126 (34 cases) for females. In the present RA material the average yearly number of sick days for the period 1963–1966 was 87 (19 cases) and 67 (72 cases), respectively

Table 45. *Percentage distribution of sick-leave days in RA and contrast groups 56–60 years. Mean number of sick days among sick-listed (C = contrast)*

Percentages in italics

	Sex	Period 1955–1958 RA	C	1959–1962 RA	C	1963–1966 RA	C
Number of persons	M	24	44	24	44	24	44
	F	95	104	95	104	95	104
Sick-leave days 0	M	*12*	*55*	*0*	*55*	*17*	*43*
	F	*22*	*41*	*28*	*41*	*22*	*38*
1–29	M	*4*	*16*	*4*	*11*	*8*	*23*
	F	*7*	*24*	*4*	*14*	*7*	*20*
30–89	M	*25*	*9*	*17*	*14*	*8*	*20*
	F	*22*	*15*	*22*	*18*	*17*	*18*
90–364	M	*46*	*20*	*50*	*18*	*33*	*5*
	F	*26*	*13*	*33*	*27*	*32*	*19*
365–	M	*13*	*0*	*29*	*2*	*34*	*9*
	F	*32*	*6*	*13*	*0*	*22*	*5*
Mean number of sick days among sick-listed	M	201±87	106±46	336±132	101±54	346±134	118±75
	F	279±72	123±45	224±56	106±23	266±61	111±34

Sick days *after* disability pension *not* included in calculations of means.
95% confidence limits of the mean

These figures indicate that the average middle-aged RA case, diagnosed in the usual way would need some 50–100% more sick days than would the corresponding RA person from a population survey. The official total average number of sick days (ref. no. 2 in the chapter on official statistics, p. 146) for the age-group 55–66 years is 46.9 days for women. As the contrast group did not contain severely sick persons and was younger the 28 mean sick days for this group argue for acceptable representativity of contrasts.

The duration of disease in age-group 56–60 is

Table 46. *Changes of sick-leave class 1955–1966*
Age-group 56–60 yrs.

Group	Grade of arm-hand disablement	Change of sick-leave class	1955–1958/1959–1962 M	F	1955–1958/1963–1966 M	F	Total no of changes M	F	Median number of sick days[a] 1955–1958 M	F	1959–1962 M	F	1963–1966 M	F
RA	No or slight (0–6)	Higher	4	20	6	20	10	40	121	47	167	64	278	62
		Same	6	13	2	14	8	27						
		Lower	2	17	4	16	6	33						
	Moderate (8–16)	Higher	4	9	2	11	6	20	153	106	327	204	252	103
		Same	2	9	3	11	5	20						
		Lower	1	10	2	6	3	16						
	Severe (18–136)	Higher	5	2	2	5	7	7	0	106	647	64	8	117
		Same	0	6	1	6	1	12						
		Lower	0	9	2	6	2	15						
Total RA		Higher	13	31	10	36	23	67	125	105	284	91	252	126
		Same	8	28	6	31	14	59						
		Lower	3	36	8	28	11	64						
Contrast		Higher	10	32	17	36	27	68	0	14	0	22	11	20
		Same	20	45	15	41	35	86						
		Lower	14	27	12	27	26	54						

Sick days *after* disability pension *not* included in calculations of medians.



Fig. 37 Individual sick days for RA and contrast men.

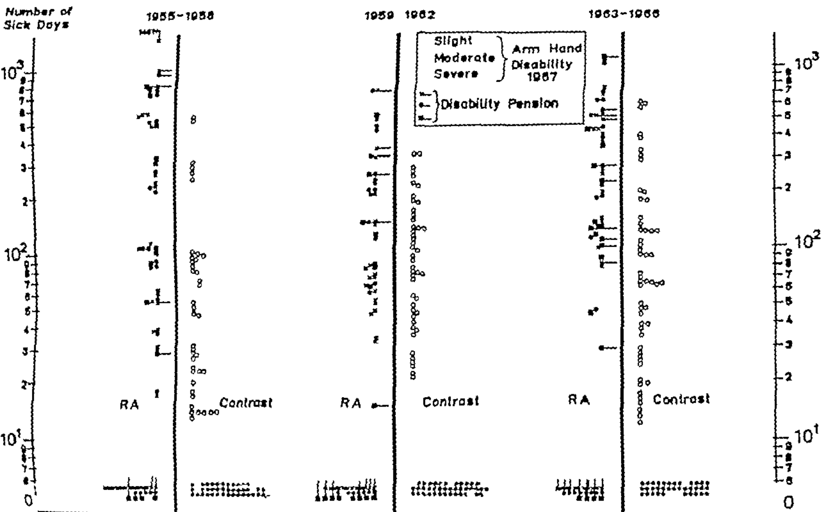


Fig 18 Individual sick days for RA and contrast women, 1955 through 1966; age-group 56–60; grade of arm-hand disability in 1967

long (Table 19 p. 60). In the period 1959 through 1966, however the time on the sick list averaged for men only 23 % and for women 17 % of total time. As the general course of the RA disease is but little influenced by therapeutic measures, these figures—disability pensioners and not sick-listed excluded—have several implications. The upper limit officially accepted for sick listing without disability pension is highly flexible. For those six RA persons who in 1963–1966 qualified for a disability pension, the range of previous sick days was 225–1 469 Even if the remittant course of RA is considered, the number of sick-leave days represents only a small part of total time spent in disease. This is of significance in the selection represented by materials based on sick-listed persons. No differences were found between gainfully employed and not gainfully employed women with respect to mean number of sick days in 1963–1966, being 216 ± 67 days and 198 ± 103 days, respectively Nor was any difference in this respect found for contrast women 66 ± 29 and 74 ± 42 days respectively (95 % confidence limits of the mean). This indicates that from the viewpoint of doctors and of insurance policy household work is as good as gainful employment. Gainfully employed men had a mean number of sick days of 300 ± 151 days in 1963–1966.

A dynamic aspect on sick leave will be seen from table 46, which also shows the median number of sick days. Sick-leave classes used are found in Table 45. A considerable turnover of length of sick periods is found, irrespective of grade of arm–hand disablement. The general pattern of turnover in the RA group does not differ from that in the contrast group. For the RA group, however the turnover takes place at a level with six to seven times higher median number of sick days than that in the contrast group. For all three periods, median number of sick days is higher for RA males than for RA females, figures are reduced by the influence of disabilit pensioners with less possibility of being listed. The median number of sick days women increased twofold or threefold between "slight and moderate" grade of disability

Individual number of sick days in RA and contrast groups in 1955 through 1966

Figs. 37 and 38 show the number of indi sick days in the RA and the contrast group for th three observation periods 1955–1958 1959–19 and 1963–1966. A concentration of more capped men is found both at a high level of s days and in the group with no sick days which it is represented by disability For women (Fig. 38) this general pattern is initely less clear and a considerable ... exists. The figures also illustrate the problem the grade of disease in a contrast group. If sons with no sick days in any period should been included, only 35 out of 148 persons w have been accepted.

Conclusions

For the RA group the median number of sic days during three periods in 1955–1966 is si times as high as that in the contrast group. How ever the turnover rate between different classes sick days is equal for the RA and the group but occurs at a higher level in the R group. Besides this turnover there is a wide dividual scatter of the number of sick days, whic only to some extent depends upon the grade disability Despite the chronicity of the RA s drome, only one-fifth of total time was spent sick leave. No differences in the mean number women and housewives.

Present survey and the selection problem

On p. 13 was presented a list of investigations which illustrate the numerous selection processes, thus producing various grades of non-representativeness in a material of diseased persons. These selections, often of importance to the conclusions, are mostly recognized intuitively but seldom quantified.

Table 47 shows eleven possible sources of information. The percentage of persons reported for a possible source is calculated on the basis of the number of persons fulfilling one or more of the 1966 criteria for RA. Even in the four-criteria group the use of potentially reliable sources means a significant selection from the population with symptoms or signs of RA. Of those fulfilling one or two criteria, only a small part would have been found if the sources had been used for finding the RA population. With respect to the presence in a particular source, the differences between respondent's interview information and source information would be estimated to be small and usually implying an underreporting (Vital and Health Statistics 1965 1966).

Table 47 *Percentage of persons in different sources based on the number of criteria for RA (1966)*

	Number of criteria for RA			
	1	2	3	4
Number ...	55	116	73	49
Ever attended doctor for joint symptoms	*82*	*81*	*85*	*98*
Hospital care since 1954	*62*	*78*	*75*	*84*
Regular doctor's visits	*60*	*52*	*48*	*71*
Hospitalized for joint symptoms	*18*	*25*	*41*	*65*
On the sick list 1963–1966 for criteria	*5*	*21*	*30*	*45*
Former inpatient of the hospitals of the National Pensions Board	*4*	*9*	*18*	*37*
Disability pension	*4*	*9*	*29*	*53*
Attending hospital or outpatient clinic doctor	*31*	*16*	*18*	*27*
Previous social assistance	*4*	*13*	*8*	*18*
Physical therapy pre-interview year	*9*	*6*	*5*	*12*
On waiting list for RA surgery	*2*	*5*	*8*	*10*

— Sources difficult to penetrate

Table 48 shows the cumulative percentages of persons who should have been found, using different numbers of the hypothetical sources listed in Table 47. The RA group was split into those fulfilling one and two and those fulfilling three and four RA criteria (1966). Table 48 shows that it would have been necessary to investigate as many as nine sources so as to identify 99% of the RA persons in the "high-criteria" group. Four sources which covered many RA people but were considered to be difficult to penetrate (marked in Table 47) were excluded in one calculation. The cumulative proportions of found persons increased much less steeply and included 50% of the "low-criteria" group as against 83% of the "high-criteria" group.

In conclusion, considerable incompleteness appeared, even when typical cases of RA were considered, using one or a few hypothetical sources in identifying RA persons. If difficultly penetrable sources, such as doctors' files, were used, much work would probably be expended on achieving a material that would still be incomplete. The results definitely argue in favour of the representativity with respect to disease pattern found in a population study.

Table 48. *Cumulative percentages for hypothetically found persons, distributed by number of sources. Number of criteria for RA*

No. of sources	One and two RA criteria 1966		Three or four RA criteria 1966	
	Using 11 sources	Using 7 sources	Using 11 sources	Using 7 sources
1	*16*	*30*	*6*	*33*
2	*37*	*41*	*22*	*53*
3	*67*	*46*	*37*	*67*
4	*79*	*49*	*53*	*78*
5	*90*	*49*	*73*	*82*
6	*96*	*50*	*82*	*83*
7	*98*		*93*	
8	*99*		*98*	
9			*99*	
10				
11				

General summary

Chapter 1 Recent official statistics on RA in Sweden and Stockholm are demonstrated. The quality of the data on mortality disability sick leave, and hospital care is discussed. A marked concentration increasing with age is found for RA patients in longer sick periods and higher ages in different sectors of sick care. Certain incompleteness of hospital statistics for Stockholm with reference to RA provokes difficulties in their interpretation.

Chapter 2 The spectrum of selection processes, which causes various grades of non-representativeness in hospital series, is surveyed. The background and development of the criteria for RA are presented. Previous Swedish population investigations on RA are briefly reviewed.

Chapters 3 and 4 The methods and realization *of the present study which took place in 1965–*1968, are described. From four age-groups, 70–74 56–60 42–46, and 31–35 years in Stockholm City 15 268 persons were chosen by random sampling. By means of a mail questionnaire on joint symptoms they were screened into five groups with falling probabilities of RA. Non-response was only 2.2 % By stratified sampling, 293 (weighted numbers) persons with RA were identified from 4 195 examined. The lowest screening level at first medical examination was *three clinical criteria for RA (Rome, 1961) and at* re-examination after 18–33 months one clinical criteria for RA (New York, 1966). The RA group thus consisted of persons with proven long-term joint disease of RA-syndrome type. From those denying joint symptoms, a representative contrast population of 456 persons was formed.

Chapter 5 Statistical considerations are presented referring to the problem of estimating the prevalence of a relatively rare disease in a population. It is concluded that data from many previous RA surveys are subjected to considerable sampling errors. Phase-sampling techniques as used in the present study will significantly reduce sampling errors in prevalence and, at the same time, a reasonable number of RA persons can be identified.

Chapter 6 Routines for joint examinati X-ray blood sampling, and blood tests are sented. Data were recorded on a joint-by basis. Besides basic data on clinical history interview forms covered occupation and hom conditions. A previously applied scheme for *classification of X rays with respect to grade* probability of RA was supplemented with the grade of involvement. Functional capacity assessed, using daily activities uniform for b sexes. Seventeen arm–hand and nine leg functi were thus assessed, applying a *four-step* grad of performance for each function. In summar ing and thus forming an arm-hand and leg ability index, severe impairment was given m weight. From official sources, data on taxable come and sick leave for the period 1955 to 19 were collected.

Chapter 7 The previous use of questions RA symptoms is reviewed. Even though su questions have been frequently applied, relativ few surveys have used them as complete screeni instruments examining both positives and ne tives. The great difficulties in converting so screening questions from one language to anoth and still retaining their meaning are exemplifi This fact influences the prevalence of joint d cases.

In the present survey 25–34 % reported jo symptoms on the questionnaire. No person wi RA was found by medical examination of t 1 201 persons stratified and randomly sampl from those denying joint symptoms. The true po tive rate for RA was low being 1 8–9.5 % those stating at least one joint symptom. In t group stating previous hospitalization for RA, 1 28 % fulfilled the screening level for the R group. A detailed presentation is given of use joint symptoms among those who previously d nied symptoms.

The questionnaire did not satisfactorily sort o persons with joint symptoms and diseases, eve though RA was well concentrated to the sympto group.

Chapter 8. Problems in forming an adequate contrast group to the RA group are discussed. The present contrast group, cleared of severely diseased persons, was matched by age and sex, and came from the same population as did the RA group. Adequate representativity and possibilities for comparisons were thus achieved.

Chapters 9 to 15 contain analyses of the significance of the present individual criteria and their combinations in forming the RA syndrome. Data from the present survey illustrate some problems.

Chapter 9 Morning stiffness of more than 1 hour's duration was common even in age-group 42–46 years, being 20 %. Both for the doctor and the respondent, morning stiffness is a vaguely defined criterion and of doubtful value in the diagnosis of RA.

Chapter 10 Joint pain is one of the most prominent symptoms of the RA syndrome. Considerable instability exists, however in individuals' reports on pain. Localization difficulties as well as false definitions applied to "pain and "tenderness" were found in the present study

Chapter 11 Joint swelling is also a difficultly delineated symptom. Joints do not have equal chances to be diagnosed as swollen, which has implications as to criteria. For age-groups 56–60 and 42–46 years, doubtful swelling was found in 8.5–26.2 % among those reporting symptoms.

Chapter 12 Limitation of joint movement is a subjective measure in population surveys. Painful limitation of the shoulder joint was diagnosed in 23.6 % of those in age-group 56–60 years.

Chapter 13 The value and implications of radiological data are discussed. It is concluded that although they are a permanent record, their use as a main indicator of RA does not solve the ultimate problem of the diagnosis. The inevitable border between a present–absent" statement and grading of severity with increasing size of erosions is stressed.

Chapter 14 Positive serological tests for rheumatoid factor are not commonly found in population materials of RA. This general finding and reports on inconsistency of serological results are reviewed, as is also the influence of age.

Chapter 15 Special problems concerning the use of groups and single criteria in a population are discussed. It is concluded that weighting is a pseudo-solution to the diagnostic problem. In the present survey exclusions were represented by 36 persons, of whom 18 had ankylosing spondylitis or Reiter's syndrome. Exclusions, as generally used, constitute a theoretically unsatisfactory but feasible solution.

A diagnosis is both a function of time and based on sometimes inconsistent data. A considerable mobility in the number of criteria between two observations was found with decreasing changeability and with increasing number of criteria.

It is generally concluded that, in spite of different definitions, the RA syndrome and thus the prevalence is dependent on many variables outside classical medicine. Age, education, semantics, and race add to established pure medical data, thus forming a RA syndrome with breadth and variation.

Chapter 16. Basic data are presented on RA and contrast groups. The prevalence spectrum of RA is in general agreement with those previously found in surveys from western Europe. Maximum prevalence was 7.2 % for females 56–60 years fulfilling lowest screening level. SSCT positivity was low being 23 % for males and 13 % for females. 47 % had radiological grade ≥ 2 for RA, which is almost twice the proportion found in the British surveys. Possible causes of this difference are discussed.

Severely disabled persons were relatively few The RA persons had one or several other chronic conditions, an aspect which is seldom considered in reports on RA.

Only 3.3 % of the contrasts were serologically positive, and this positivity was age-dependent and independent of joint symptoms.

Chapters 17–19 Aspects of joint pattern are discussed on the basis of data from the present survey

Chapter 17 The interrelationships between the 1961 and the 1966 criteria for RA are presented. It is concluded that the criteria of 1966 are stricter than those of 1961 Sometimes, however considerable overlappings exist between the two sets. Morning stiffness does not contribute to the diagnosis of RA in applying the 1966 criteria.

Chapter 18 General problems of joint-pattern analysis are outlined. Findings in single joints and joint groups are analysed, as is the coexistence of pain and erosions. In the presence of bilateral erosions, there is significantly less pain in typical non-RA joints than in RA joints. The joint tern outlined in RA criterion no. 2 of J therefore relevant.

Chapter 19 In the literature, joint involvement and pattern are seldom presented in exact terms, which has implications as to comparisons between and within materials. A set-up of generally applicable definitions and terms is proposed and exemplified by data from the present survey The terms consider site and type of involvement, symmetry and spread of involvement (cumulation). Several results of the joint-pattern analysis confirm the adequate splitting up into RA and non-RA joints and indicate some areas of overlapping. Joint-pattern analysis shows that radiological OA changes contribute comparatively little to the symptoms in the RA group.

Chapter 20. The interrelationships are analysed for eight measures on disease progression and disability For these eight measures a step-wise multiple regression analysis indicated three areas of closer interrelationships, namely between grade of subjective disease trouble and number of painful joints, between Steinbrocker functional class and arm–hand disablement, and between the radiological stage and number of deformities. This has implications as to prognosis, which virtually always considers pure medical data.

Chapter 21 The general background of the employment situation in the RA group is outlined with special reference to womens' participation in the labour market. It is concluded that the participation of RA persons in the labour force is highly dependent on general economic climate and grade of industrialization. The rapid increase of the proportion of women in the labour force is especially pronounced in Sweden with its highly differentiated industrial and commercial life.

Some published reports on gainful employment and RA are reviewed. No direct correlation between employability and stage of disease was reported by most of the investigators.

The difficulties in assessing the grade of disability of housewives are also commented upon. Many medical investigators, however seem to look upon the women with RA as a problem *not* with respect to gainful employment but only to household work. The development of the labour market in the industrialized countries makes this view less valid.

Chapter 22 Gainful employment and its background data are presented. In the present study one out of four persons fulfilling three or four criteria for RA drew a disability pension. Th[e] proportion of disability pensioners increased fo[ur]fold with increasing age. In comparison with t[he] contrast group, the RA group had significant[ly] lower proportions of persons both with pos[t] elementary schooling and with more qualified [oc]cupations. RA men changed work significant[ly] more than did contrast men. Gainfully employ[ed] were found in all grades of disability RA wome[n] preserved an employment rate similar to that [of] contrast women, but RA men were significant[ly] less economically active than were contrast me[n]. On the basis of the eight indices on disease p[ro]gression and disability it is concluded that th[e] average *severely* disabled RA man was gainful[ly] employed to the same extent as was the averag[e] *moderately* disabled RA woman.

Chapter 23 Some of the few detailed report[s] on the economic situation of sick persons a[re] reviewed.

In the present survey taxable incomes for 195[5], 1960, and 1965 were chosen as an appropriat[e] measure on economic assets. The average incom[e] of the RA persons increased during these years The age-group 56–60 was chosen for a speci[al] study The mean incomes for RA men were statis[ti]cally significantly lower than for contrasts, bu[t] only for 1965 For RA women the mean income were the same as for contrast women and wer[e] not significantly influenced by grade of arm–han[d] disability Several changes of income classes oc[c]urred during the observation period. Economi[c]cally RA men were relatively harder hit by th[e] disease than were RA women. There were, how ever great individual ranges of income, employ[-]ment, and social conditions.

Chapter 24 Difficulties in comparisons of sick-leave data are outlined. The sick-leave development for 1955 through 1966, divided into three periods, for age-group 56–60 is analyzed. Even though a concentration to >90 days was noted in each of the three periods, a considerable change from lower to higher number of sick days and vice versa was recorded. The RA case diagnosed in the usual way would need some 30–50% more sick days than would the corresponding RA person from a population survey Individual sick-day development for RA men shows a higher number of sick days with increasing arm–hand disability but for women this pattern is definitely less clear

Chapter 25 The hypothetical use of 11 or 7

sources and their influence on selection is described, using cumulative percentage of persons found. It is concluded that the use of difficultly penetrable sources contributes the greatest number of RA persons. Sources that are actually penetrable would have yielded only 50–83% of RA persons, depending on the number of criteria fulfilled. To achieve the full pattern of the RA syndrome a population survey is therefore necessary

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Appendix I

Proposed diagnostic criteria for use in population studies. Rome, 1961

(The Epidemiology of Chronic Rheumatism. Eds. J. H. Kellgren, M. R. Jeffrey & J. Ball. Blackwell Scientific Publications, Oxford, 1963.)

1. Morning stiffness.

2. Pain on motion or tenderness in at least one joint (observed by physician).

3. Swelling (soft tissue thickening or fluid, not bony overgrowth alone) in at least one joint (observed by physician).

4. Swelling (observed by physician) of at least one other joint (any interval free of joint symptoms between the two joint involvements may not be more than 3 months).

5. Symmetrical joint swelling (observed by physician) with simultaneous involvement of midphalangeal, metacarpophalangeal, or metatarsophalangeal joints is acceptable without absolute symmetry). Terminal phalangeal joint involvement will not satisfy this criterion.

6. Subcutaneous nodules (observed by a physician) over bony prominences, on extensor surfaces or in juxta-articular regions.

7. X-ray changes typical of rheumatoid arthritis (which must include at least bony decalcification localized to or greatest around the involved joints and not just degenerative changes). Degenerative changes do not exclude patients from any group classified as rheumatoid arthritis.

8. Positive agglutination test—demonstration of the "rheumatoid factor" by any method which, in two laboratories, has been positive in not over 5% of normal controls—or positive streptococcal agglutination test.

The proportion of individuals fulfilling given number of criteria—one, two, three, four, etc.—should be reported to give the full gradient of disease. In those fulfilling three or four criteria the diagnosis is "Probable" in those fulfilling five or six it is "Definite" and in those fulfilling seven or eight "Classical"

Inactive rheumatoid arthritis

1. A past history of polyarthritis.

2. Symmetrical deformity of peripheral joints consisting of ankylosis or irreducible subluxation, especially of the lateral metatarsophalangeal or metacarpophalangeal joints. There must be some involvement of one hand or foot. Involvement limited to large joints, such as the elbows or knees, does not satisfy this criterion.

3. X-ray changes of rheumatoid arthritis of grade 2 or more.

4. Positive serological test for rheumatoid factor. The diagnosis is "Definite" if three or four of the above criteria are fulfilled, and "Probable" if two criteria are fulfilled.

Criteria for rheumatoid arthritis. New York, 1966

(Bull. Rheum. Dis. 17 1967)

General Principles

1 To avoid semantic confusion, it is important that term such as RA be applied only to that condition that consensus would recognize as RA. Essentially this means restricting the term to a syndrome that clinical rheumatologist would diagnose as RA in a patient seeking professional advice, and to coin or adopt simple descriptive titles for other sets of criteria.

2. To ensure continuity in data yielded by surveys, it is desirable that the characteristics enumerated in *both* the sets of criteria listed under RA should continue to be observed.

3. The omission of any characteristic from the criteria recommended hereunder should not be regarded as licence not to study the distribution of that characteristic. Thus, although subcutaneous nodules, for instance, are no longer included in the suggested criteria, it is eminently desirable that the presence or absence of such characteristic, or of any other characteristic feature of disease, should continue to be recorded.

4. The two sets of criteria should not be regarded as definitive criteria, but are offered as hypotheses or models that require validation by all concerned in the field.

Criteria for Polyarthritis

1. Complaint of morning stiffness, elicited by question based on the format used by Cobb, and qualified by location in the limbs and by duration of not less than quarter of an hour (15 min.), but which must not be present all day. It is probably desirable to record the duration of morning stiffness as the raw observation.

2. Pain on motion or tenderness in joint (with the exception of the back, but including the neck).

3. Swelling (soft tissue thickening or effusion, but not bony overgrowth) in joint.

4. Swelling in another joint.

5. Symmetrical joint swelling (i.e. simultaneous swelling of the same joint or group of joints on both sides of the body: involvement of two or more proximal interphalangeal (PIP), metacarpophalangeal (MCP), and metatarsophalangeal (MTP) joints need not be absolutely symmetrical; distal interphalangeal (DIP) joint involvement does not satisfy this criterion).

Do you wake up with stiffness or aching in your joints and muscles?

Criteria 2–5 inclusive must be observed by the examining physician, and particular care should be taken in the interpretation of swelling of ankles, knees and the PIP joints.

Criteria for Rheumatoid Arthritis

1. A history past or present, of an episode of joint pain involving three or more limb joints, without stipulation as to duration. For the purposes of this criterion, the joints on either side shall count separately but joints that occur in groups (e.g. the PIPs or MCPs on one side) shall count only as single joint, even if more than one of them is involved on the same side.

2. Involvement by swelling, limitation, subluxation or ankylosis of at least three limb joints (excluding the DIPs, the fifth PIPs, the first carpometacarpal (CMC) joints, the hips and the first MTPs) with symmetry of at least one joint pair. There must be involvement of one hand, wrist or foot, as involvement limited to large joints such as elbows or knees does not satisfy this criterion. Subluxation of the lateral MTPs must be irreducible.

3. X-ray features of grade 2 or more erosive arthritis in the hands, wrists, or feet.

4. Positive serological reaction for rheumatoid (anti-gammaglobulin) factor, determined by method that is controlled by periodic testing of reference sera and by exchange f sera with other laboratories.

Appendix II

Non-participation problems

General remarks

Two different types of non-participants can be defined, namely those individuals or groups of individuals who have been actively excluded and those who should have been included in the investigation but, for several reasons, was not. Special sampling procedures regarding the problem of non-participation were not used. Data relating to the non-participation problem refer to the investigated groups as a whole. On the other hand, the investigated groups might be the results of a sampling procedure.

To achieve maximum efficiency in tracing RA cases, the investigation of the groups reporting joint symptoms was given special design. The maximal efforts were directed towards these groups with a supposed high concentration of RA cases which is clearly seen in Fig. 6 p. 20.

A person with great experience of tracing people in non-participation groups worked successfully on securing respondents. Home visits were used only in a limited number of cases because of the success in bringing people to the examination centre. The different steps in the investigation are presented in Fig. 4 p. 19. The non-participation in different groups is summarized in Appendix table 1.

Different non-participation groups

Not included in the population (1.0–4.5% Appendix table 1 and 2)

The population under study was defined as follows. 1) The participant must be registered with Stockholm City Population Register, and 2) domiciled and living in Stockholm on the date on which the questionnaire was mailed to him. The group not included in the population, averaging 2% of the sample, will thus consist of persons who had moved out of the city and of those who had died (Appendix table 2). The great number of dead in the oldest age-group, 81 persons, is explained by an error in the census register tape, which contained the names of several persons who had died [illegible] few years earlier. The number of those who had moved from the city of Stockholm increases with decreasing age, which is in accordance with official statistics.

No response to questionnaire (1.4–2.9% Appendix tables 1 and 2)

The majority of those who did not answer the questionnaire could not be traced. The lowest figure for non-response is found in age-group II, being 1.4%. Different reasons for non-participation are noted in Appendix table 2.

Reporting joint symptoms but not examined (8.4–11.1% Appendix tables 1 and 2)

Fig. 6 p. 20 illustrates the proportion of persons not examined among those reporting symptoms. The smallest proportions of those not examined (0–8.4%) are found in the two groups with the highest proportion of RA cases (see chapter on the function of the screening instrument p. 36). One exception to this respect is subgroup 2, age-group III, in which only 5 more individuals would have been required for the pattern to be the same as for the other age-groups.

Different reasons for non-participation are listed in Appendix table 2. The main reason for non-participation in this group is refusal. Other reasons were stated (no time, gainful employment, etc.), but were not accepted,

Appendix table 1 *Examined persons and non-participants*[a]
Weighted numbers

Age-group yrs.	Sample investigated	Not included in population	%	No response	%	Reporting symptoms: Examined Yes	No	%	Denying symptoms: Examined Yes	No	%
I 70–74	2 201	100	4.5	35	1.6	934	102	9.8	473	380	44.9
II 56–60	3 394	34	1.0	49	1.4	1 563	159	9.2	1 171	417	26.3
III 42–46	4 731	61	1.3	109	2.3	1 399	146	8.4	2 334	492	17.5
IV 31–35	4 940	109	2.2	145	2.9	1 222	134	11.1	2 650	648	19.8
Total	15 266	304	2.0	338	2.2	5 317	541	9.5	6 819	1 929	22.0

[a] Re-examined groups excluded.

Appendix table 2. *Reasons for non-participation. Questionnaire groups and groups reporting joint symptom*

Age-group Years Number	I 70–74 2195				II 56–60 2399				III 42–46 4775				IV 31–35 4899			
	Questionnaire		With symptoms 1036	For re-examination 83	*Questionnaire*		With symptoms 1721	For re-examination 149	*Questionnaire*		With symptoms 1745	For re-examination 74	*Questionnaire*		With symptoms 1376	For re-examination 21
	Not included in population	No response	Not examined	Not re-examined	Not included in population	No response	Not examined	Not re-examined	Not included in population	No response	Not examined	Not re-examined	Not included in population	N response	Not examined	N t re-examined
Not traced	—	13	11	—	—	32	38	1	—	91	31	2	—	128	22	—
Moved within Sweden	17	—	5	—	13	3	6	—	45	4	25	—	36	—	35	—
Emigrated	2	—	—	—	3	2	—	—	11	1	1	—	59	3	6	—
Abroad	—	1	2	—	4	4	—	—	5	6	10	—	11	8	10	—
Refused	—	3	65	4	—	1	83	—	—	3	69	—	—	2	69	—
Sick	—	3	14	—	—	6	25	—	—	3	10	—	—	3	11	—
Dead	81	15	5	9	14	1	7	1	—	1	—	1	3	1	1	—
Total	100	35	102	13	34	49	159	2	61	109	146	3	109	145	154	—

Appendix table 3. *Results of examination of samples of those denying joint symptoms*

Unweighted numbers

Age-group ...	I		II		III		IV	
Years ...	70–74		56–60		42–46		31 35	
Number	344		530		389		331	
Sampled for contrast group ...	Yes	No	Yes	No	Yes	No	Yes	No
Examined								
Females	67	68	107	102	76	67	74	67
Males	23	66	47	135	44	134	34	90
Total	90	134	154	237	120	201	108	157
Male proportion of examined (%)	*25 6*	*49.3*	*30.1*	*57.0*	*36.7*	*66.7*	*31.5*	*57.3*
Completion rate %	*66.7*	*64.1*	*75.9*	*72.5*	*84.5*	*81 4*	*86 4*	*76.2*

since every facility that could reasonably be expected was provided (e.g. money, taxis, examination on convenient spot). In my opinion, the grouping of different reasons for non-participation which is often done in surveys of this type will reflect not the true situation but social behaviour. This was stressed by *Factors Related to Response in Health Examination Survey United States, 1960–1962.* (National Center for Health Statistics, Ser. 2, No. 36, 1969).

Denying joint symptoms but not examined (17.5–34.9% Appendix tables 1 3 and 4)

As it could be predicted that non-participation among those denying joint symptoms would be higher than among those reporting symptoms, several special measures were taken to reduce the effect of this non-participation. Since the contrast group was extracted from those denying joint symptoms, it was very important to understand the structure of this non-participation problem. By telephone interviews rough estimation was made concerning the joint symptoms in the group as whole. The non-participation in the groups which answered or did not answer the requestioning on joint symptoms at the telephone interview is presented in Appendix table 4. Those who refused to participate predominate. None of those who had died had had RA, according to the death certificates. The heading "no time is used here, as the same service could not be offered to these persons as to the symptoms-reporting groups.

Every other woman and every fourth man were sampled in advance from the groups to be examined among those denying joint symptoms (Appendix table 3). The search for non-participants was concentrated to those sampled for the contrast group. This method resulted in somewhat higher participation in this group (10.2–2.6% Appendix table 3, last line).

Not re-examined and fulfilling three or more clinical criteria of RA at the first examination (0–16% Appendix table 5)

The structure of this group is important in the assessment of the results from the final groups of RA persons and

Appendix table 4 *Reasons for non-participation in groups denying joint symptoms*

Unweighted numbers

Age-group ...	I		II		III		IV	
Years	70–74		56–60		42–46		31 35	
Number ...	344		530		389		331	
Re-questioned on joint symptoms	Yes	No	Yes	No	Yes	No	Yes	No
Not traced	—	7	—	6	—	5	—	10
Moved within Sweden	1	1	3	3	2	3	8	4
Emigrated	—	—	—	—	—	—	1	—
Abroad	1	—	4	—	2	1	3	1
Refused	46	1	86	1	19	1	18	1
Sick	23	—	15	3	6	—	1	2
No time	—	—	1	—	23		17	—
Miscellaneous	5	2	6	—	3	—	—	—
Dead	1	32	1	10	1	2	—	1
Total	77	43	116	23	56	12	48	66
	120		139		68			
Percentage of available	*22.4*	*12.5*	*21.9*	*4.3*	*14.2*	*3.3*	*14 7*	*5 1*

Appendix table 5. *Persons with ≥ 3 clinical criteria for RA (Rome 1961) and not re-examined*

Age group	Sub-group	Person no	Sex	No. of clinical criteria at first examination	SCAT	AFT	X-ray grade for RA	Functional class	Comments
Dead									
I	1	67	F	6	1/80	1/160	3	3	RA for more than 20 years; died 18 months after first examination in chronic nephritis
I	1	372	M	6	1/1280	1/2560	4	4	RA for 10-20 years, died 14 months after first examination from CHD
I	1	1046	F	6	1/160	1/320	3	3	RA for more than 20 years, died 20 months after first examination from CHD + pneumonia
I	1	1147	F	5	1/640	1/640	4	4	RA for 43 years; died 12 months after first examination from peptic ulcer and RA
I	1	1292	M	5	1/20	1/80	4	3	RA for 10-20 years; died 23 months after first examination from RA
I	1	1541	F	6	1/40	1/160	4	4	RA for unknown period died 23 months after first examination from CHD
I	1	2028	F	4	1/320	1/2560	N X-ray	3	RA for 5-10 years; died 15 months after examination from general arteriosclerosis
I	2	45	M	5	Negative		2	2	RA for more than 20 years; died 5 months after examination from CHD
I	2	2077	F	5	1/80	1/160	4	4	RA for 25 years, died 24 months after examination from CHD
II	2	838	F	3	Not performed		No X-ray	3	RA died 21 months after first examination from CHD + pulmonary embolism
III	2	264	F	5	Not performed		No X-ray	3	SLE with uremia died 14 months after examination from coronary infarction
Not retraced									
II	2	554	M	5	Not performed		1	2	1958 and 1961 in a mental hospital
III	1	4302	F	5	Negative		0	1	Searched for in six places
III	1	1796	F	4	Not performed		No X-ray	2	1959–1962 in mental hospital on four occasions
Refused reexamination									
I	1	1209	F	4	Negative		2	2	Hospital care in 1954 for RA
I	2	263	F	5	Not performed		N X-ray	3	Severe obesity
I	2	473	F	5	Negative		2	2	Threatened author with police
I	2	806	F	5	Negative		0	2	Arrived from the USA in 1960

Appendix table 6. *Ratio of males/females (%) in some examined and not examined groups*

Age-group, yrs.		70–74		56–60		42–46		31 35	
		I	%	II	%	III	%	IV	%
Not examined									
With symptoms[a]	M	29	28	77	48	85	58	94	61
	F	73		82		61		60	
Not in the population	M	48	48	15	44	51	84	70	64
	F	52		19		10		39	
No response to questionnaire	M	18	51	34	69	80	73	101	70
	F	17		15		29		44	
No symptoms	M	47	39	61	44	40	59	36	53
	F	73		78		28		30	
Examined									
With symptoms[a]	M	301	32	587	38	633	40	473	39
	F	633		974		966		749	
No symptoms	M	89	40	182	46	178	55	124	47
	F	135		209		143		141	
RA group	M	7	11	32	22	12	18	6	29
	F	57		111		53		15	
Contrast group	M	21	25	44	30	44	38	34	31
	F	63		104		72		74	

[a] Weighted numbers.

timelines presented on an individual basis in Appendix table 5. Eleven persons died during the observation period. Nine of them had severe clinical rheumatoid arthritis. One of the remaining two had long-standing joint symptoms fulfilling the criteria of classical RA but was only slightly incapacitated; the other one was later found to have SLE with uraemia. Nine out of 11 dead were originally included in the oldest age-group and, thus, represent a non-participation of 11% consisting of persons with a severe disease. Although some data were available, these cases were not included in the final groups of RA persons, so as to assure greatest possible homogeneity of the final RA groups. The conclusions on joint pattern (p. 70) should be viewed against the fact that this group of severely disabled persons is not included. To some extent, certain social-medical factors are also specific for this group.

Out of the 9 dead in age-group 70–74, only 7 had visited a doctor regularly. The same number had been hospitalized for RA at least once. Only 2 had received physio-therapy in the last year. Seven had seen a doctor within 6 months of the onset of their joint disease. All 9 lived in modern flats.

The remaining 7 not re-traced and refusers, although not being severely disabled, were not "normal" persons, as will be seen from the comments in Appendix table 5.

Summarizing, the non-participation in this group influences only the final results in age-group 70–74. This influence is moderate and in several respects its magnitude and quality are known.

Fig. 1 Proportion of not married in different examined and not examined groups.

Special comparisons to throw light on the structure of the non participation groups

Proportion of males to females (Appendix table 6)

Since RA is more common among women, the proportions between the sexes in the groups examined and not examined are of some interest. Generally it can be said that the unexamined groups contain proportionally twice as many men as does the examined groups, which is the common finding in several investigations from Sweden (Dalenius, 1968). This would probably mean that the proportion of RA in the non-participation group is smaller than in the examined group. However it must be taken into consideration that the non-participation group probably includes homeless men, in whom Inghe (1958) found RA prevalence of 6.75%. The criteria for RA used by Inghe, however were not the same as those used here. In the group denying symptoms, the differences in the proportions of the sexes between examined and not examined are insignificant, which is essential with respect to the contrast groups.

Civil status (Appendix fig. 1)

A common opinion is that married people are under-represented in non-participation groups. This is the case for age-groups II–IV but the reverse holds true for age-group I.

Incomes (Appendix fig. 2)

For those sampled for the contrast group but not appearing for examination, information was obtained from the income-tax returns for 1965 for the respondent as well as for the spouse. Appendix fig. 2 illustrates the pattern of income, expressed as the differences in proportions of

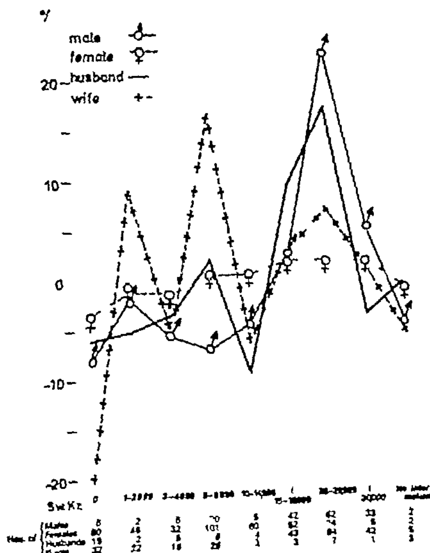


Fig. 2. Differences in proportions between examined and not examined persons in different income classes (symptom denying groups).

income classes between examined and not examined in the symptom-denying group (1 US$ 5.20 Sw. kronor). For *females* there is no difference but for *males* an under-representation among examined exists in lower income classes (below 15 000 kronor) and an overrepresentation in incomes (15 000–30 000 kronor). For husbands the pattern is the same as for the males.

Sick-leave data

Data on sick leave for the period 1963–1966 were collected from the local Social Insurance Office for those sampled for the contrast group but not examined. No marked differences between examined and not examined groups were noted.

Conclusions

The analysis of the non-participation problem justifies the following general conclusions:

1. Non-participation distributed by sex, civil status, incomes, and sick-leave data showed some, but not important differences between non-participants and examined. These differences speak for a low RA prevalence in some of the non-response groups.

2. Non-participation in the questionnaire part of the survey was low and probably comprised few cases of RA.

3. By concentrating the resources available for tracing non-participants on groups with high proportions of RA persons, few RA cases were probably missed.

Appendix table 7. Persons with > 3 clinical criteria for RA at first examination and excluded from the RA group at re-examination

Age-group	Sub-group	No. of criteria (Rome 1961) Patient no.	Sex	No. of clinical criteria: Rome (1961) Examination *First*	New York (1966)	*Second*	SCAT	AFT	X-ray grade for RA	Functional class	Comments
I	2	821	M	4	2	0	1/40	Negative	0	2	OA
I	2	1122	F	4	0	0		Negative	No X-ray	2	Polymyalgia rheumatica 1965
I	2	1337	M	3	0	0		Negative	2	2	Cerebral haemorrhage with aphasia at re-examination
I	3	1799	F	3	2	0		Negative	No X-ray	2	Gonarthrosis (weighting number 2)
II	1	662	M	4	2	0		Negative	No X-ray	2	Severe obesity gonarthrosis
II	1	3309	F	3	1	0		Negative	No X-ray	2	Gonarthrosis
II	2	465	F	3	0	0		Negative	1	2	Psoriasis, toxic goitre
II	2	1458	F	3	1	0		Negative	1	2	Heberden nodes, nervousness
III	1	3014	M	4	2	0		Negative	No X-ray	2	Traumatic arthrosis of ankle
III	2	1143	F	4	3	0		Negative	0	2	Gonarthrosis
III	3	391	M	4	0	0		Negative	1	2	Severe obesity OA (weighting number 4)

4 Non-participation was relatively high among those having symptoms, being highest in the oldest age-group. By concentrating the resources in tracing non-participants on those sampled for the contrast group, the non-participation in this group was slightly reduced.

5 The non-participation group which has the greatest [illegible] on the general conclusions was found among those in the highest age-class who were primarily examined. This group included 9 persons (11%) who were severely incapacitated by RA and who died later on. Some pertinent data on these persons are known, however. Results from the oldest age-group should therefore be interpreted with caution because of the non-participation, both in the contrast and the RA group.

Appendix table 8. *Excluded from contrast group because of RA-resembling joint symptoms*

Age-group	Person no	Sex	No. of clinical criteria (New York 1966): Poly-arthritis	RA	SCAT	AFT	Comment
I	270	M	1	2		Negative	Clinical OA symptoms for two months
I	473	M	1	2		Negative	Clinical OA symptoms for two months
II	1028	F	1	1		Negative	Multiple joint pain of OA. Operated on for pulmonary TB
II	2325	F	2	1		Negative	Multiple joint pain of OA for several years
III	259	F	1	1		Negative	Multiple joint pain, no swelling or limitation of movements
III	3968	F	2	1		Negative	Multiple joint pain for some months

Appendix table 9 *Excluded from contrast group because of severe disease*

Age-group	Person no.	Sex	Diagnosis	Comments
I	348	F	Total blindness	Blind for two years, in home for aged
I	561	F	Organic neurologic disease	Marked spastic paresis of extremities, walks with extreme difficulty; ECAT and AFT negative
I	1296	F	Cardiac insufficiency	Marked symptoms of cardiac insufficiency; diabetes; deafness
I	1300	F	Parkinsonism	Advanced disease
II	123	M	Schizophrenia	In mental hospital for over 20 years
II	1060	M	Amputation	Traumatic amputation of hand
II	1128	M	Amputation	Advanced cerebral arteriosclerosis; hemiplegia, left leg amputated
II	1828	F	Sequelae after accident	Ankylosis of knee; muscle atrophy; major crush injury of foot with pain
III	986	F	Amputation	Traumatic amputation of whole left arm
III	3030	F	Uraemia	Chronic pyelonephritis with many hospital stays; treated with artificial kidney for six months

Excluded persons

Fulfilling three or more criteria for RA at first examination but healthy at re-examination (Appendix table 7)

The persons in whom RA was diagnosed at the primary examination were re-examined 18–33 months later. It was then found that 11 did not fulfill any of the clinical criteria for RA (1966) and, thus, did not meet the requirements for long-standing disease of RA type. Most of them had localized symptoms of OA. None of them fulfilled five clinical criteria (Ropes, 1961) at the first examination.

Suffering from RA-resembling symptoms and other severe diseases (Appendix tables 8 and 9)

One of the chief objects of this investigation was to measure social and individual effects of a long-standing joint disease of RA type. It is therefore natural that the group used for comparison should not contain persons with definite, severe, long-standing diseases. Two principally different types of cases were therefore excluded from the contrast group.

One group (Appendix table 8) includes 6 persons with joint symptoms of RA type, fulfilling up to two criteria for polyarthritis and two criteria for RA (New York, 1966). Those with two criteria for RA (1966) should not be included in the RA group, as their diseases started after they had received the questionnaire. It must also be considered principally unsatisfactory to include patients with RA-resembling syndrome both in the contrast groups and in the RA group. This means that in the contrast group no one fulfills RA criterion 2 (Table 22, p. 61).

The other group (Appendix table 9) comprises 10 persons with severe unmistakable diseases who, according to the principles given above, should be excluded from the contrast group. Thus, the contrast groups will be somewhat "healthier" than the average population of Stockholm of the same ages.

Appendix III

Form for first examination of those fulfilling three or more clinical criteria for RA (Rome, 1961)

1. Number of clinical criteria 3 4 5 6
2. Definite RA (Rome, 1961). Yes no
3. Erythrocyte sedimentation rate (mm in an hour) –5, –10, –15, –20, –30, –50, –75, –100, ≥125.
4. Steinbrocker functional class I II III IV
5. Case for operation: Hand, yes, no
   Foot, yes, no
   Knee, yes, no
6. What do you consider the greatest hindrance to you in your daily life? 1) Deformities of hands. 2) Deformities of knees. 3) Other alternatives.

Form for first interview of RA group

(Questions indicated by bold-faced figures were also made to the contrast group.)

1. Sex

Civil status
Not Married
r
Widowed

Number of live-born children

Number of whole brothers and sisters (including dead ones)

The respondent was born as number among his/her brothers and sisters

2. What is your present main employment or occupation? 1) 2) Housework (not for the respondent alone). 3) Pensioner with regular gainful employment. 4) Pensioner with occasional gainful employment. 5) Pensioner not gainfully employed. 6) Student. 7) Other alternatives.
3. Did you do any wage-earning work last week (last seven days)? 1) 40 hours or more. 2) 30–39 hours. 3) 20–29 hours. 4) 10–19 hours. 5) 1–9 hours. 6) No work because of unemployment. 7) No work because on sick leave. 8) No work for other reasons
4. Have you had any (other) gainful employment before? 1) Yes. 2) No. *If "yes"*: a) what was the designation of that work? b) when were you last gainfully employed? 1) In 19 (year).
5. Have you changed employment because of your rheumatism? (contrast group [any disease]) 1) Yes, from to 2) No.
6. (If ever gainfully employed) Have you been working more than year in your last occupation? Yes, no.
7. Have you any education beyond elementary school? 1) No, only elementary school. 2) Lower grammar school, junior high school, people high school, girls' school. 3) Higher secondary school. 4) University
8. Have you any additional vocational training? 1) No. 2) Yes, a) for what occupation, b) what school or course, c) for how long did the training last?
9. For how long have you had your rheumatism? 1) 5 months or less. 2) 6–11 months. 3) 12–23 months. 4) 2–4 years. 5) 5–9 years. 6) 10–19 years. 7) 20 years or more.
10. Has any of your parents or brothers or sisters ever had rheumatoid arthritis? Yes, no.
11. Have you ever seen a doctor for your rheumatism? Yes, no.
12. For how long did you suffer from rheumatism before consulting a doctor? 1) 3 months or less. 2) 6–11 months. 3) 12 23 months. 4) 2–4 years. 5) 5–9 years. 6) 10–19 years. 7) 20 years or more.
13. Are you at present on sick leave for rheumatism? No. If "yes" for how long? 1) 4 weeks or less. 2) 5–8 weeks. 3) 9–11 weeks. 4) 3–5 months. 5) 5–11 months. 6) 12–23 months. 7) 2 years or more.
14. Have you earlier been on sick leave for rheumatoid arthritis for at least one year and after that period resumed your work? 1) Yes, for year(s). 2) No.
15. Are you at present drawing disability pension for rheumatoid arthritis? No. If "yes": a) for how long were you sick before you received a disability pension? 1) less than 23 months. 2) 24–35 months. 3) 36–48 months. 4) 5–9 years. 5) 10–19 years. 6) 20 years or more. b) how long ago did you begin to draw your disability pension? 1) 5 months or less. 2) 6–11 months. 3) 12–23 months. 4) 2–4 years. 5) 5–9 years. 6) 10–19 years. 7) 20 years or more.
16. Are you receiving any form of social assistance? Yes, no. If "no" have you earlier had help through the social services? Yes, no. If "yes" for how long? 1) 4 weeks or less. 2) 5–8 weeks. 3) 2–5 months. 4) 6–11 months. 5) 1 year or more.
17. Have you ever been hospitalized for your rheumatism? Yes, no.
18. How long had you been ill when you were first hospitalized? 1) 5 months or less. 2) 6–11 months. 3) 1–2 years. 4) 2–4 years. 5) 5–9 years. 6) 10–19 years. 7) 20 years or more.
19. How many times have you been hospitalized because of rheumatism? 1) Once. 2) Twice. 3) Three times. 4) Four times. 5) Five times or more.
20. Have you stayed in any of the hospitals of the National Pensions Board? Yes, no.
21. Are you now under regular medical supervision (at least two visits year)? Yes, no.
22. Are you taking any of the following drugs 1) Acetylsalicylic acid, yes, no. 2) Phenylbutazone, yes, no. 3) Antimalarials, yes, no. 4) Injections of gold, yes, no. 5) Cortisone or ACTH, yes, no. 6) Other [illegible] rheumatic drugs not included above, yes, no.
23. Are you taking drugs for rheumatism without consulting doctor? Yes, no.

24. Are you receiving physical therapy? Yes, no. If "no have you had any physical therapy in the last twelve months? Yes, no
25. Have you ever been treated abroad for your rheumatism? Yes, no.
26. What is your opinion of the cause(s) of your rheumatism (you may mark out up to three causes)? 1)Hereditary disposition 2) Hard work 3) Damp working place. 4) Draughts 5) Poor housing conditions 6) Infection 7) Accident 8) Pregnancy 9) Menopause 10) Other cause (specify)
27 Were you an inpatient in hospital or any other institution on March 1 (1965, age-groups I and II, 1966, III and IV)? 1) No. 2) Acute hospital. 3) Hospital for chronic diseases. 4) Home for the aged.
28. Fo how long have you then been an inpatient (up to March 1)? 1) 4 weeks or less. 2) 1–2 months. 3) 3–5 months. 4) 6–11 months. 5) 12 23 months. 6) 2–4 years. 7) 4 years or more.
29 Have you consulted homeopathist, chiropractor nature healer, etc., because of your rheumatism? Yes, no.
30. Do you live in 1) A house of your own. 2) A flat in a house. 3) An ordinary flat in multi-family house. 4) A pensioner's flat in multi-family house. 5) A flat in block of pensioner' flats. 6) A special flat for disabled. 7) A flat in home run by the parish. If you have no permanent accomodation, do you live 8) As lodger 9) In a hotel, boarding-house, etc. 10) Other alternatives.
31. How many persons (including yourself) live in the same place? 1) Living alone; 2, 3, 4, 5 persons or more.
32. Do you share accomodation with 1) Spouse. 2) Children of your own 18 years old or older. 3) Children of your own under age. 4) Parents or parents-in-law 5) Other adults. 6) Other minor children, infants.
33. For how long have you had your present accomodation? 1) 11 months or less. 2) 12 23 months. 3) 2–4 years. 4) 5–9 years. 5) 10–19 years. 6) 20 years or more.
34. How big is the place at your disposal? 1) 1 room with facilities for cooking. 2) 1 room and a kitchenette. 3) 1 room and kitchen. 4) 2 rooms and kitchen. 5) 3 rooms and a kitchen. 6) 4 rooms and a kitchen. 7) 5 or more rooms and a kitchen.
35. On which floor do you live? 1) Ground floor. 2) 1st floor. 3) 2nd floor. 4) 3rd floor 5) 4th floor or higher.
36. (If living in multi-family house) Is there a lift? Yes, no.
37 Is there running water 1) In your flat. 2) In the house but not in your flat. 3) No running water in the house.
38. Is there run-off in your flat? Yes, no.
39. Is there central heating? Yes, no.
40. Is there 1) A bathroom for your own use. 2) A shower bath for your own use. 3) A common bathroom. 4) Neither
41. Is there a. 1) W.C. of your own. 2) Common W.C. 3) Earth closet of your own. 4) Common earth closet.
42. What are your monthly expenses for accomodation (Sw kronor) 1) Less than 50 kr 2) 50–99 kr. 3) 100–179 kr. 4) 180–199 kr. 5) 200–299 kr. 6) 300–399 kr. 7) 400–499 kr. 8) 500 or more.
43. Have you or your family (answer for every item "yes or "no") 1) A car 2) A TV-set. 3) A radio. 4) A telephone. 5) A daily newspaper.
44. Have you had any help with the housework from persons outside your household in the last month? Yes, no.
45. If "yes" was this help 1) A servant or housekeeper. 2) A home-cleaning help. 3) A relative (outside your household) or neighbour. 4) A qualified home-help. 5) An unqualified person from the organization "Help-for-the-old service 6) A home-sister. 7) Other alternatives.
46. Help has been received 1) Daily 2) Twice week. 3) Once a week. 4) Once every other week. 5) On one occasion.

Appendix IV

Form for re-examination and re-interview of RA group

1. Criteria for polyarthritis (New York, 1966) 0 1 2 3 4 5.
2. Nodules. Yes, no.
3. Criterion for RA (New York, 1966) 0 1 2.
4. Joint examination (Scheme of individual joints)
5. Psoriasis. Yes, no.
   Major diseases
6. Data on excluded persons
7. Blood-pressure (mmHg)

Systolic	Diastolic
1) under 120	1) under 80
2) under 140	2) under 90
3) under 160	3) under 100
4) under 180	4) under 110
5) under 200	5) under 120
6) under 220	6) under 130
7) > 220	7) > 130

8. Deformities 0) No definite deformities 1) Ulnar deviation 2) Swan-neck deformity 3) Symptom at compression of median nerve 4) Ulnar-head syndrome 5) Contracture of flexor tendons in hand 6) Boutonnière's deformity 7) Painful shoulder with limitation of movement 8) Dislocation of metatarsal head (-s) 9) Hallux valgus 10) Pronounced flat-foot 11) Contraction of knee 12) Baker's cyst.
9. Have you ever had cortisone injections in joints or tendons? Yes, no, don't know
10. Need for physical therapy 1) No or insignificant need for physical therapy 2) Fairly dependent on physical therapy 3) Dependent on physical therapy 4) Urgent need of physical therapy
11. Need of small operation (hands, feet) 1) No case for operation 2) Suitable for and willing to undergo operation 3) Suitable for but not willing to undergo operation.
12. Need of major operation (knees, hips). 1) No case for operation. 2) Suitable for and willing to undergo operation. 3) Suitable for but not willing to undergo operation.
13. Need of care for joint disease as an outpatient. 1) No need or need of visits less than once year. 2) Check-up once a year. 3) Check-up twice year 4) Check-up four times year 5) Check-up more than four times year
14. Need of care as an inpatient 1) No need of inpatient care. 2) Need of care within half year. 3) Need of care within three months. 4) Need of care within one month. 5) Need of immediate care.
15. Would you describe your rheumatic complaints as causing you (compare yourself with your contemporaries without joint disease): 1) No or slight trouble. 2) Fairly slight trouble. 3) Moderate trouble. 4) Fairly great trouble. 5) Great trouble. 6) Very great trouble.
16. Do you feel that you receive adequate and sufficient care for your rheumatism at present? Yes, no, don't know
17. Do you believe that your rheumatism would be improved during a long stay in warmer climate? Yes, no, doubtful.
18. Are you on a waiting list for operation on your joints? Yes, no, don't know
19. Do you feel that your rheumatism is dependent on season? Yes, no, don't know
20. Do you feel that your rheumatism is dependent on the weather? Yes, no, don't know
21. Do you feel that your rheumatism is influenced by changes in the weather? Yes, no, don't know
22. Do you feel that your rheumatism has been permanently improved by any sort of treatment? Yes, no, don't know
23. Examinee accepts special investigation for receiving aids for activities of daily living (ADL devices). Yes, no.
24. Have you been working more than five years in your last occupation? Yes, no.
25. What was your father's occupation when you were about 15 years old? 1) Occupation 2) Don't know or no contact with father at that age.
26. If you are not gainfully employed at present, do you intend to start working within year or so? Yes, no.
27. Are you drawing a disability pension? No. Yes, because of since
28. Were you born in Stockholm? Yes, no.
29. Were you born in Sweden but outside Stockholm? Yes, no. Born abroad.
30. Have you been an inpatient any time since 1954? No. Yes, because of number of times.
31. Did you feel calm and confident as patient in hospital? Yes, no.
32. Suppose your were ill and your doctor said that from medical viewpoint you could just as well be treated at home as in a hospital. Which would you prefer 1) T be hospitalized. 2) To be taken care of at home.
33. Do you feel that the expense plays decisive part in your choice of doctor? Yes, no
34. Are you under the care of doctor at present? Yes, no.
35. Is this doctor 1) Working in private practice outside hospital. 2) Working in hospital. 3) A medical officer of health or your works doctor 4) A doctor at an outpatient department. 5) Are you seeing two or more doctors. 6) Other alternatives.
36. What kind of doctor would you prefer if you were suffering from long-term disease which did not require frequent hospital care? 1) A private practitioner

2) A hospital doctor. 3) A doctor at an out patient department. 4) Other alternatives

37 Would you avoid getting help through the social services, even if you were entitled to it, and instead try to get temporary help from relatives, neighbours or friends? 1) Yes 2) No 3) Doubtful.

38. Do you feel that, being in an economically troublesome situation, you are naturally entitled to social assistance? 1) Yes 2) No 3) Doubtful.

39 Would you prefer to move from your present accommodation? Yes, no.

40. I should like to know your opinion about the quality of your place, its equipment and neighbourhood.

	Satisfactory	Acceptable	Not acceptable	Not relevant
1. Size				
2. Rent in relation to size, equipment, etc.				
3 Equipment and general standard				
4 Room temperature				
5. Neighbourhood				
6. Communications				
7 Distance to a food shop				
8. Your opinion of the housing conditions and neighbourhood on the whole				

41. Is there anything special lacking in standards, equipment or other respects that makes it inconvenient for you to live there? Yes, No.

42. Are you on the waiting list for 1) Another place? Yes, no 2) Accommodation in home for aged people? Yes, no. 3) Admission to hospital? Yes, no. 4) Accomodation in another institution

43. Are you troubled with any long-term chronic disease (besides rheumatism)? 1) Yes 2) No.

44. Did you vote in the last general election (1966)? Yes, no.

45. Which party do you sympathize most with (not necessarily vote for)? 1) Conservatives. 2) Christian democrats. 3) *Liberals.* 4) *Centre Party* 5) Social democrats. 6) Communists. 7) None or refuse to answer

46. Do you often feel nervous or worried without any particular reason? Yes, no.

47 Do you often feel cut off and isolated from other people? Yes, no.

48. Do you like to complete task in every detail before you leave it, or in other words, are you pedantic? Yes, no

49 Have you generally difficulties in falling asleep at night? Yes, no.

50. Do you believe that you are generally more tired than your contemporaries? Yes, no.

51. When you have personal problem, can you turn to your relatives and/or friends with confidence and hope for their understanding? Yes, no, don't know

52. Weight kg with/without clothes.

53. Height cm with/without shoes.

54. SSCT titre

55. *AFT titre*

56. Which word would you prefer in describing a longstanding hurtful feeling (in out Dage) in a joint 1) Pain. 2) Tenderness. 3) Ache.

57 What do you mean by *tenderness* in a joint?
   a) That it hurts *without* anyone touching the joint? Yes, no.
   b) The same as an ache? Yes, no.
   c) That it hurts when anyone *touches* the joint? Yes, no.
   d) Can one have pain and tenderness at the same time? Yes, no

58. What do you mean by *pain* in a joint?
) The same as *tenderness*? Yes, no.
   b) That it hurts without anyone touching the joint? Yes, no
) That it hurts when anyone *touches* the joint? Yes, no.
   d) Can one *have pain and ache at the same time*? Yes, no.

59 What do you mean by *ache* in a joint?
) The same as *tenderness*? Yes, no.
   b) That it hurts *without* anyone touches the joint? Yes, no.
) The same thing as *pain* Yes, no.
   d) Can one have *ache* and *tenderness* at the same time in joint? Yes, no.
) That it hurts hen anyone *touches* the joint? Yes, no.

Appendix V

Functional capacity

Unless otherwise stated, each function is graded as follows.

Grading

	Score
1. Without appreciable difficulty	0
2. With some difficulty	2
3. With great difficulty	4
4. Unable to manage this function	8

A. *Scheme for functional capacity of hands*

1. Use safety-pin
2. Knot shoe-strings
3. Use table knife for spreading butter on bread
4. Use tablespoon for eating soup
5. Drink out of glass
6. Turn knob on electrical stove
7. Wind up wrist-watch
8. Comb hair
9. Wash neck
10. Do up button
11. Undo button
12. Write
13. Put on trousers
14. Manage press-button
15. Manage water-tap
16. Manage telephone
17. Put on shirt (blouse)

B. *Scheme for functional capacity of legs*

1. Do you at present go out
   1. Daily or almost daily
   2. Once or twice a week
   3. Once or twice a month
   4. Less than once a month or not at all
2. Can walk *without* support
   1. 100 m or more
   2. 15–100 m
   3. Only a few steps
   4. Unable to walk without support
3. Can walk *with* support
   1. 100 m or more
   2. 15–100 m
   3. Can only stand up or take a few steps
   4. Unable to stand even with support
4. Can walk up and down stairs *without* support
5. Can walk up and down stairs *ith* support
6. Can get up from chair *without* support
7. Can manage urination and defaecation without help
8. Can enter a bus
9. Can use an escalator
10. General mobility
    1. Not bedridden or confined to wheel chair
    2. Confined to wheel chair but can move ove to bed without help
    3. Confined to wheel chair and unable to move over to bed without help
    4. Bedridden

Appendix VI

Special notes on examination of joints

Hand. The examinee was asked to open and to close the hand, to flex and to extend the wrist, which was considered as an entity. Pain on active and passive movements was recorded. The opposition of the thumb against the base of MCP V was especially considered.

Elbow. Continuous palpation during extension, flexion, and rotation with the lower arm flexed at 90°.

Shoulder. Initially maximal abduction and maximal inward and outward rotation of the upper arm in the horizontal position were considered. If there was no history of joint pain in the shoulders *and* the movements described above were judged as being normal, no palpation of the shoulder was made. Absence of limitation of movement in a painless shoulder would initially always imply no swelling or tenderness. Humeroscapular and acromioclavicular joints were therefore examined only when positive history pain, or limitation of movement were recorded.

Hip. Passive rotation in the hip joint was performed with the examinee in the sitting position. The range of abduction was similarly investigated. Hip joints were not palpated in the screening procedure, because the additional information thus obtained was judged to be of no significance in detecting disease.

Knee. The examinee was in the sitting position. The range of movement investigated was 90° flexion to full extension. Rotation was performed with the knee flexed at 90°. If crepitations were noted, the examinee was re-questioned on any past history of knee symptoms. Crepitations as the single finding did not qualify for a diagnosis.

Ankle. In this investigation the ankle comprised both the talo-crural and the subtalar joint. Maximal passive extension and flexion as well as pronation and supination were performed. The examinee was always questioned on history of trauma.

Big toe. In age-group I, 70–74 years, the toes were not examined if a negative history was reported. The great prevalence of hallux valgus in this age-group was at this stage of the survey considered to be of peripheral interest. However from age-group II, 56–60 years and onwards the toes were routinely examined. The range of motion considered was passive movement both in MTP I and in DIP I.

Second – fifth toes. For toe joints other than MTP II–V fair clinical examination and recording of results is extremely difficult. Except for unequivocal findings, these recordings imply low reproducibility and high subjectivity.

Appendix VII

Serological tests

Test procedures

The tests were performed at Stockholm City Bacteriological Laboratory.

All the samples, totalling about 1 000, were investigated over one period, January–March 1968, and by one person, who did the work only and was familiar with the methods used.

The tests applied were AFT (Carlson 1939) and SSCT (Waaler 1960). The test procedures were those used routinely for several years at this laboratory.

The internationally most widely employed scheme for dilution (1/4, 1/8, 1/16, 1/32, etc.) was not applied. It was felt more essential not to change well-established routines than to achieve strict *formal* conformity with other investigators. Thus, the dilution scale 1/10, 1/20, 1/40, 1/80, etc., was applied.

Controls used

Freeze-dried standard serum of RA factor was obtained from the International Laboratory for Biological Standards (WHO Expert Committee on Biological Standardization 1969). It was diluted with 1 ml of distilled water. This RA standard serum turned out to be positive for SSCT at 1/80 and for AFT at 1/640 on two separate occasions.

In every set-up (altogether 14) one known negative serum and three known positive sera from clinically advanced cases of RA were used. Positive controls were generally stable, maximum variation being one step of dilution.

Recording of results

SSCT was considered positive at a dilution of 1/20 or higher. For AFT the corresponding dilution was 1/40.

AFT-positive reactions at 1/20 or 1/10 were recorded as negatives, according to the routine of this laboratory.

Appendix VIII

Need of ADL devices

Official regulations

In Sweden ADL devices are principially free of charge if prescribed by a doctor or for some devices, by a district nurse. The devices are distributed by hospitals or by some special agencies. A free testing for helping the patient to convenient devices as well as to their correct use is recommended but not compulsory The patient' travelling expences in connection with this testing are usually not refunded.

Present survey

Every respondent, irrespective of grade of disability was informed on the idea of ADL devices. Examples of their range of usefulness were taken from the respondents own disability

A physiotherapist, working for this investigation only performed the testing at the Stockholm City Disablement Resettlement Bureau. Full equipment fo testing and provision was available.

Expenses for travelling to the Bureau were payed by funds of the RA investigation, and individual appointments could be made immediately This meant great advantage to the respondents, in comparison with the normal routine. Further details will be published elsewhere. (Allander E., to be published.)

Appendix IX

Offical data

Sick leave

The source of this information was the "F-card". Each individual has an F-card at the local Social Insurance Office. Sick-leave periods, number of sick-days, and diagnoses are noted currently on these cards. The period from 1955 to 1966 was considered suitable for providing valid information on disease as reflected by official statistics.

The period was divided into three four-year periods, 1955–1958, 1959–1962, and 1963–1966. Each period was regarded as an entity. The diagnoses were split up into "RA" and "non-RA". Under the heading "RA" were included different designations implying definite RA disease. The heading "non-RA" included not only diseases of quite different origin, such as cholecystitis, but also osteoarthritis, periarthritis, Reiter's disease, and allied conditions.

As RA is a disease that usually means long periods of sick leave (see p. 109), periods of 7 days or less were considered separately.

The total number of sick days for each four-year period did not include these periods of 7 days or less. The validity of the diagnoses in the 7-day periods is low as they are mainly reported by the patient and are not the result of medical examination, which is not required for receiving sick benefit for 7 days only.

If a patient was drawing a disability pension, this was recorded for the period in question. Those who draw disability pensions are entitled to free hospital care for that period but generally excluded from sick benefits.

However, official separate recording of hospital care was not performed uniformly during 1955–1966. Exact information in this respect was technically available but practically difficult to obtain, and was therefore omitted in the present investigation.

The administrative rules for social insurance were changed in different ways during the observation period. Generally speaking, increased sick benefits as regards money, term, and services have been introduced. Details on the structure of these changes will not be discussed here.

Income

Interview information on income was discarded, although Berglind (1968) found good agreement between interview information and revenue data. Income-tax returns were not available for the RA investigation.

From the register of taxpayers in Stockholm City information on "taxable income for national income-tax levy" was collected for the respondent and spouses both in the RA and in the contrast group, for 1955 1960, and 1965

For several persons who had earlier been domiciled outside Stockholm City information was collected from local taxpayers offices. 98.6% of incomes were thus recorded. The rest concerned mainly persons in the age-group 31 35 years from 1955, at that time living abroad.

Details of the defects of these income figures as a measure of "true income and assets is beyond the scope of this investigation. However, the recorded figures provide some basic information suitable for group or sometimes for individual comparisons. On request, the Ministry of Finance produced tables for conversion of "taxable income for national income-tax levy" into figures for "true" income. These tables, however, are valid only under certain conditions. It was not possible to estimate total assets of individuals. The influence of personal property on group assets is rather small, however. According to as yet unpublished figures from the State Commission of Inquiry on Low Incomes (Johansson, 1970, personal communication) for married couples 20–66 years old, only 17% own more than 50 000 Swedish Kronor, mostly in the form of residential property. For those not married the corresponding proportion is about 7%. Half the number of married couples own less than 10 000 kronor

Civil status

Data on civil status in 1955, 1960, and 1965 were also obtained from the taxpayers' register.

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